



**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference Agenda
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Agenda for January 8, 2002

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LEE ANN RAMSEY: This is Lee Ann. I think the beeping I keep hearing is someone has us on hold. June Holstrum cannot be with us today.

I'd like to thank each of you for joining us for the early hearing detection and intervention call. I hope that you each enjoyed a wonderful holiday season and are looking forward to the new year as we are. Before we begin, I'd like to remind you to please place your phone on mute when you're not speaking. And please don't put us on hold if your phone plays music. And also, before we begin, if each of you could address your name before you ask a question or make a comment, that will help our transcription service.

And are there any announcements before we start our scheduled agenda? Okay. If not, then I'd like to open up the call with Marcus Gaffney, who is going to talk about our Caption First service information. Marcus?

MARCUS GAFFNEY: Good afternoon. I would like to just remind all of our speakers to please say their names before they start their presentation so the caption writer knows who is speaking. This will make it easier people using the caption service to know who is speaking. Thank you for your assistance with this.

LEE ANN RAMSEY: Is Janet on the line?

JANET DesGEORGES Hi everyone. I'm Janet DesGeorges. I'm a parent of three children, ages 15, 12 and 10. My youngest daughter is Sara. She was identified at the age of 2 with a moderate/severe hearing loss. She is now in fifth grade at our neighborhood school and she is very active and on the student council, working her way towards "master of the universe", apparently.

I'm really happy to be here with all of you today. Happy New Year. One of my major resolutions this year is to stay within time allotted for any given presentation. And so I'm going to talk to you today about parent involvement and universal newborn hearing systems. Unfortunately, there is no way in 10 minutes I can get through all the information I would love to share with you. So I'll do the best I can in 10 minutes and then if you want to hear the rest, you'll just have to invite me to your state, especially if you live in a warm climate near the beach. I'd be happy to come and share the rest of the information with you.

I'm going to work a little backwards today about parent involvement in early hearing detection and intervention systems. In terms of when we think of the goals of what we hope to achieve in newborn hearing systems, we typically think of the goals such as: screening by one month of age; diagnostics by three months; enter into early intervention by six months; reducing refer rates; and increasing efficacy of equipment; and things like that. These are all meaningful goals and necessary for success. But really the true goal of what we're talking about and why we are gathered here today goes beyond those "EHDI goals". For me as a parent, when I think of my daughter sitting in the audience of her high school or college graduation, with her diploma in hand, waving back to me, mouthing or signing the words "thanks, mom," knowing that that diploma was the result of a good education, is the true goal and sign of success in Early detection and intervention.

As a parent, the dismal outcomes for Deaf and hard-of-hearing people today exiting their education, are a real threat to success. Statistically speaking, I as a parent can expect my daughter to graduate with a 2.9 reading level, have a 30 percent chance of graduating as a Deaf or hard-of-hearing student being functionally illiterate as a result of today's current school system.

Yesterday I had the opportunity to speak to the largest school district in Colorado around the need for education reform. One of the teachers raised her hand as I was speaking, and she said, "you know, these are the same issues that we were facing 30 years ago and nothing has really changed". And I assured her, as I assure those of you here today: Huge changes have occurred, not the least of which is universal newborn hearing systems and

the ability to identify infants early on. The outcomes that we can hope and expect as parents and professionals, for our kids as a result of newborn hearing screening, is that they will enter school with language development within the norms of typically hearing kids .

Along with early intervention and advances in new technology, also, I would include in “what’s changed”, is the impact of positive deaf culture and community, probably starting with the “Deaf President Now” movement at Gallaudet University. All of those things have shaped this field in the last 15 years, where I think we are on the threshold of changes not just at the point of early identification, but all the way through to the outcome that we can hope for, for our children and the families that we're trying to impact through this implementation of newborn hearing systems.

I think what has come out of these changes, really, is a new breed of parents that have never existed before. There is a great term, I read in an article that I'd like to talk a bit about, calling parents today "accidental activists." In "Wired" magazine in September of 2001 there is an article called "The Citizen Scientist." It is a computer and technology magazine that was really talking about the impact the Internet has had on consumers, especially in the medical field in the last ten years.

Seven years ago, the National Library of Medicine, which disseminates the abstracts of research, was getting about 7 million hits a year. Today, on an annual basis, they're getting 360 million hits a year, and a third of those being consumers. I bring that up because I think for the first time research is being made available and the outcomes of research is being made available to the typical consumer. And when you think about the research that is driving this system, which is showing that if we can identify babies at an early age, the outcome for these kids, the potential for these kids, has been raised like never before.

When we look at the outcomes of the education system as it currently exists, you know that system was working from a deficit model in that most of those kids were entering school age at a two to three year delay. Today we have the opportunity with the establishment of effective newborn hearing systems to have kids enter at a level of language appropriate skills of typically hearing kids.

What I am trying to put together for you today about parent involvement is that what we're finding here in the State of Colorado, as parents who have had kids early identified and are approaching the school age years, with kids with normal developing language, these parents are informed, have high expectations and are really beginning to push the edge of the envelope on how the educational system needs to respond to these kids.

Now, let's work backwards from those parents who have now felt the effects of early identification, to how parents can be involved in the establishment of effective universal newborn hearing systems. There was a physician quoted in the WIRE Magazine article, Dr. Tom Ferguson, who said the traditional mantle of authority has been shaken. What he was talking about is that one of the outcomes of the Internet has been that parents have opportunities to talk with other parents, learn advocacy, and get up to date information. This has really altered the encounter between doctors and patients, or professionals and parents, really, forever.

So I think the question isn't should we involve parents in the building of this system. I would say parents will be involved and like any really good system should be consumer driven. And so then I think all of us who are involved in the creation and establishment of these systems need to really look and understand how we can harness parent involvement, positive parent involvement, through meaningful partnerships in the building of these systems.

And I think by giving parents the opportunity, and including parents to have the opportunity for training so that they are effective, appropriate and really sophisticated in the understanding of what it's going to take to make sure that the system is flowing from the family's point of view and the process and all the components that need

to take place in order for these systems to come together, we need to look at how we can get parents involved in a meaningful way.

I think it's an emerging field. I think there are parents, advocates or parent consultants popping up all over the country in universal newborn hearing systems. And I think it will be some time as we kind of develop this and give parents the opportunity to be meaningfully trained. Our involvement as parents stem from the foundation of our own personal experience with our kids. We then use that as a metamorphosis into a really positive ability to look beyond our own personal experience, to give input into this system in a broader sense.

Without parents, the system will never be fully realized. Parents have been underrepresented at the level where decisions are being made which will effect their children. Parents are overseeing the programs and watch dogging the quality of the programs. We as parents want to make sure that our kids have the opportunity to succeed at the potential that we know these kids can achieve. And I really believe that passion and that understanding can help to create the foundation of that promise, which is early identification and newborn hearing systems.

How do you get parents involved? Well, first of all, you have to give them the opportunity. In a survey done of 388 early intervention programs, 9 percent reported that they had parents on staff. 5 percent reported parents were paid as consultants, 13 percent reported parents were on advisory boards. The list goes on. Really, the statistics of true meaningful parent participation is dismal, although it is growing. So I think you need to look at ways you can give opportunities to parents to be meaningfully involved.

And then training is such a key component. And here in Colorado we have effectively started to train parents through opening the doors of professional in service training and allowing parents to come in and hear state of the art updates in technology, for instance. And so in a sense the parents are being trained right alongside with professionals as new emerging things come into the field. That has been one way that we have provided the training opportunity.

I'll close now, because it's been ten minutes and I'm trying to keep on my goal of -- my new year's resolution. But anyway, CDC did develop a 25 page document written by Barbara Raimondo about effective collaboration and collaboration between Deaf and hard-of-hearing families with Deaf and hard-of-hearing children. It's a meaningful way to get families involved. There is, of course, national information through the Institute for Family Centered Care on how parents can get involved. And I think it starts with an attitude of equity, saying, "we will bring parents into this process and the decision-making process in meaningful ways". Equity of financial compensation in order for families to be effectively trained, there has to be someplace in the system to fund some parents to really work meaningfully within your system.

In Colorado we went from one parent consultant position for ten hours a month, to having seven parent consultants around the state that are compensated for their time. The impact that we're making is helping to fill the gaps of the system that we are trying to create here, and that involvement is really changing the face of this system.

So anyway, thank you for your time, and I appreciate the opportunity to share with you today on parent involvement.

LEE ANN RAMSEY: Thank you for your time, Janet. I'd like to open up the floor for any questions or comments for Janet?

GAIL TIENNA: This is Gail Tienna from Illinois. I'm curious as to the funding for these parent consultants. We are suffering the same things that a lot of states are suffering, and that is losing money, losing dollars, losing

programs. How do you finance these parent consultants?

JANET DesGEORGES: That's a really good question. I think we have done it effectively through a variety of means. This system has really effectively collaborated with our existing parent organization here in our state. And we get funding from the department -- you know, it's kind of a patch work, really, of funding. We get support from the Department of Education, from the State School for the Deaf and the Blind, through MCH grants that have been written, through CDC grants that have been written. I think it's become kind of a standard of care in this field of newborn hearing systems that when a grant is being written, that we look at ways we can write in parent involvement to whatever part of that system we are looking at in the grant writing.

We are funded through grants. The parents have gotten together and taken some accountability and responsibility for writing our own grants to public and private foundations and we have had quite a bit of success there, also. Like I said, we started in this state really with the ability of somebody eeking out in their budget, you know, 10 hours a month and it's just really grown from there.

LEE ANN RAMSEY: This is Lee Ann. Any other questions or comments?

Ellen Amore: This is Ellen Amore from Rhode Island. My question is: We actually have several parent consultants and we have a fairly well developed parent consultant program and I'm specifically interested in the training that you feel would be important around EHDI issues. In particular, how you train parents to effectively understand your existing system and how they can participate in the discussions of policy and other discussions.

JANET DesGEORGES: Right. That's probably been one of the biggest learning curves we have had here, and I think from my own personal experience and then as we have brought other parents on, like I had mentioned in my presentation, the ability to really go -- for a while the only criteria, really, for pulling in a parent was if they were a parent of a deaf or hard-of-hearing child, and we have learned over time that there are some other criteria.

The ability to see beyond your own personal experience- I'm not minimizing that, I'm bringing that to the table- but the ability to represent families who have personal experiences that are different than yours. And I think the training really comes from opportunities for parents where there are discussions happening around systems being developed.

So if there is a statewide advisory task force, for instance, where you are discussing all the different issues, to make sure that a parent has an opportunity to attend that. Obviously there is no degree that we can go to school for, in a sense. But I think it has been a conglomeration for the parents in our state to have a variety of different training. Some that were in effect around parent leadership that was established by our state part C. Other kinds of workshops and training we have personally put together and heard different good speakers, and then just have trainings for our parents.

But I would say the biggest opportunity has been for our -- myself, personally, and for our parent consultants in the region in training is to attend national and state conferences for professionals on these issues, and to really learn from that venue, and that's been really effective.

LEE ANN RAMSEY: Thank you very much. Has Dr. Karl White joined us yet?

KARL WHITE: Yes. I'm on Lee Ann.

LEE ANN RAMSEY: Okay. Thank you. Dr. White is going to share with us some examples of statewide EHDI evaluation.

KARL WHITE: KARL WHITE: Thanks, Lee Ann. To help me in presenting this information, we put a Power Point presentation on our website at <http://www.infanthearing.org/slideshow/cdc/> And if you are where you can link to a computer at the same time you are on the phone, you can go to that website and at the top of the home page there will be a link to click for the CDC conference call. That will take you to a page where it says "begin slide show" as one of the options. Click on that option and select the screen resolution which your computer is using, and you will see the first slide for our discussion. At the top of each slide is a counter that tells you which slide is showing. I'll refer to those during the presentation so you can be at the same place as I am. There is an arrow to the right-hand side to go forward and an arrow to the left-hand side to go backward if you get off count.

Lee Ann and June asked me to talk about the work we have been doing with several different states in conducting statewide EHDI evaluations. As most of you know, those of you with MCHB grants are required to do an annual evaluation of your efforts to implement a statewide EHDI program. And we work now with three different states in actually doing such evaluations, and in each case we have used a similar format that I will describe to you today as one possible model for doing such an evaluation.

Slide 2 summarizes the different activities and sources of data used in the evaluation. First, there were a series of questionnaires B one questionnaire that went to all hospitals in the state, another went to a sample of physicians, and several different forms of a questionnaire were with parents of babies who had been born during the last year. Some of those babies had passed the inpatient newborn hearing screening, some were referred on the inpatient and passed the outpatient, and some referred on both the in and outpatient evaluations.

The second component of the evaluation was an analysis of the particular computer-based data management system that that state happened to be using, and in the example I'll show you today, we analyzed data for a 2-1/2 year period, 1999, 2000, and then part of 2001.

The third component consisted of site visits to a number of hospitals in the state. The instruments used in the evaluation are on our website under the program evaluation tools link and are available for other people to use if they would like to.

As shown in slide 3, we analyzed the results of that evaluation with respect to the six different components identified by MCHB as being essential for a comprehensive EHDI program. Since this evaluation was funded with MCHB money, we wanted to be sure to respond to each of those different components that are listed there in slide 3.

Slide 4 summarizes results with regard to the first component B screening all newborns for hearing loss prior to one month of age. In the particular state I am discussing today, all of the hospitals in the state had universal newborn hearing screening programs. During the two and a half year period reported here, they successfully screened 98 percent of all live births. Almost all the hospitals in this state use a two-stage OAE screening process, so we expect that the pass rate for the inpatient screen would be above 90 percent. The pass rate was a little lower than that and hadn't changed much over the last three years.

Interestingly, there was a significant number of physicians in the state who didn't realize that they had a statewide newborn hearing screening program. 25 percent of them estimated that less than 60 percent of the babies in the state were screened.

Slide 5 indicates that only about half of the people assigned by the hospital to coordinate newborn hearing screening had actually been allocated time to do that work as a part of their hospital job. For the other half, they

were expected to just manage the program in addition to everything else that they were doing. There was no specific time allocated to it.

It was also a serious concern that about 30 percent of the babies who needed an outpatient screen did not complete those screens within a reasonable period of time. Those data had also remained fairly constant over the three-year period.

Slide #6 summarizes a lot of data about the efficiency of the screening program, and I won't go into this in detail. But I want to highlight that if you look at the 10 most effective hospitals in the state (some were small, large, rural, some were located in cities), there were clearly examples of hospitals who were doing an excellent job in all areas with very low inpatient refer rates, with very high outpatient completion rates, able to follow up on most of the children who needed it. But there were also examples of hospitals who were really struggling in all of those areas. These data were very useful in helping the state advisory group and the state Department of Health to target some of their in-service efforts and support they were providing to hospitals. In this particular state, all hospitals are visited by the Department of Health on an annual basis. But these data enabled them to target extra help to those hospitals who were struggling.

Interviews with staff in the state Department of Health indicated that it was very difficult to get audiologists to report all of the results of the diagnostic evaluations because it was on a voluntary basis at the beginning of this three-year period. As a result of the data collected in this evaluation, the state decided to add to the regulation that accompanied their legislation that all audiologists would be required to report the results of those evaluations.

Slide #7 summarizes other data regarding the diagnostic evaluation. When physicians were asked what they would do with a child who didn't pass the screening test, almost all of them said that they would immediately refer that baby for a diagnostic evaluation. But interestingly, there were a significant number of physicians who estimated that you couldn't do a definitive test of hearing until the baby was 3 or more months old, indicating that there is education that needs to be done. Similarly, many hospitals didn't do any real follow-up with the babies after they referred to the physician, assuming that the physician would take care of it. And at least in terms of what parents remembered, and that may be different from what actually happened, but only about half of the parents remembered that they were given names of audiologists or referred to their physician if their baby did not pass the final screening.

Slide #9 provides information about babies who were diagnosed with hearing loss. Only about two-thirds of the hospitals keep track of whether babies with hearing loss become enrolled in early intervention programs. Again they assume that once the baby has been referred, someone else is taking care of it. Most of the hospital program coordinators didn't know what alternative early intervention programs were available in their area, so it was difficult for them to talk to parents and answer their questions. Emphasizing the need for physician education was the fact that about half the physicians estimated that you couldn't fit a baby with hearing aids before six months of age.

Slide #10 shows data related to the linkage between EHDI programs and the medical home. All of the physicians were aware that their hospital had a universal newborn hearing screening program and thought it was a very valuable service. So even though they didn't realize that all other hospitals in the state were doing newborn hearing screening, they knew that their hospital was. Most program coordinators felt that they knew who the actual primary care physician was for babies who did not pass. Interestingly, only about a third of the physicians felt that their hospital was doing a good job of educating physicians about the EHDI program, and most said that they would like more information.

Slide #11 shows how physicians responded when they were asked to assume that they had an infant patient who was diagnosed with a moderate to profound bilateral hearing loss, but no other indications. In the questionnaire, they were asked whether they would refer that baby for an ophthalmological, genetic, or otolaryngological evaluation. Interestingly, only about a fifth of them realized that they should refer such babies for an ophthalmological evaluation, about a third for a genetic evaluation, and most of them (94%) said they would refer the baby to an otolaryngologist. So again, there is a need for additional education of physicians.

Slide #12 addresses issues related to providing families with culturally-competent support. Most parents were glad a hearing screening was done. Those who remembered getting information about the EHDI program thought it was attractive, well-organized, and in the right amount of detail. Almost all parents (95%) whose babies didn't pass next said they knew what to do, and 85% said when they had questions, they were answered very well.

Slide #13 shows that most parents were very positive about the newborn hearing screening program. Interestingly, though, if you look at slide 11, which does a separate analysis for parents of just those babies who didn't pass the inpatient or outpatient screening, there is much greater concern and focuses on the fact that we probably need to do a better job with the parents of babies who do not pass. In general, hospitals in this state were doing a pretty good job, but when the baby doesn't pass the hearing screen, there is definitely more information that parents need and want.

As summarized in slide #15, only about half the parents remember being given information about the screening program, and they would have liked to have had more. This doesn't mean hospitals were not giving information to parents, but it suggests they were not doing it in a way that parents noticed it. Parents tend to get overwhelmed when they leave the hospital, and we may need to find more effective ways of giving newborn hearing screening information to parents. For example, about half of all parents didn't know their hospital had a newborn hearing screening program before they were admitted. Many of the programs didn't have information in Spanish. A significant percent of parents whose babies required diagnostic evaluations said that the tests were very difficult to pay for, that the experience was scary and confusing, that they didn't know where to get help when they needed it. Slide #16 shows that there were also weaknesses with how tracking and follow-up were being done. Most people thought the computerized tracking and data management system used by the state was very useful, but they were unaware of many of the program's features. About 25 to 50 percent didn't check to see if babies who didn't pass the screening received a diagnostic evaluation. Interestingly, program coordinators, when they just were asked to report how many babies came back for an outpatient screening, estimated it to be about 85 percent. But the tracking program showed it was only about 68 percent. In other words, program coordinators tended to be a little more optimistic about what was happening.

When asked to rate the support from the state Department of Health, almost everybody felt extremely positive about what the department had been doing for them as shown on slide #17. Respondents did target some areas with respect to financing the cost of screening and data management and tracking, where additional help would have been useful.

Conclusions from the evaluation are summarized in slide #18. Certainly a lot of progress has been made and a foundation has been established for achieving excellence. There are excellent models in the state for each component of EHDI, but only a few programs have really put it altogether. One of the most valuable parts of this evaluation has been helping the state to target where they needed to put their resources.

Parents and physicians were very supportive of the EHDI program. All the stakeholders said that they needed better information about resources and the benefits of EHDI programs. Very importantly, there were a significant number of hospitals still struggling with high refer rates. Many babies were still not completing the diagnostic and intervention process.

Slides 19-21 summarizes the recommendations for hospitals, the state Department of Health, and physicians. Clearly, there are many areas where improvement is needed, but there are also many important accomplishments. One of the real values in a systematic evaluation is to be able to identify the areas where improvements can be made, and that is certainly the case here.

Slide #22 summarizes in a cartoon way just how much work we have left to do. We have certainly come a long way, but systematic evaluation of these programs can be one of the tools which shows us where gaps exist and what needs to happen next.

That is the end of the presentation. If there are questions, I'd be happy to respond.

BEPPIE SHAPIRO: Karl this Beppie in Honolulu. How long do you plan to keep the slide show on the website? Because there are other people that I would like to see it. I can print it out now if it won't be up for at least a couple months.

KARL WHITE: We will leave it up there permanently. But it probably will be under our link after about 2 weeks. It will be under the link for slide shows and videos. On the home page there is that link. It will be there indefinitely.

WASHINGTON STATE (unknown speaker): Have you published these data?

KARL WHITE: No. There is a technical report that we gave to each of the states where we have done it and the evaluation instruments are available for downloading off the Web. If you're interested in getting a copy of the written report, send me an e-mail and I'm sure the states would be happy to send it.
Do you have plan to publish?

KARL WHITE: Yes. These data were just completed a couple weeks ago, so we will be preparing it for publication soon.

PENNY HATCHER: Karl, this is Penny in Minnesota. I have a question. Was this one state that you surveyed?

KARL WHITE: The results I just showed you were one state. We have done it in two other states.

PENNY HATCHER: The question for that one state, in their mandate, did they mandate hospitals to follow up the infants?

KARL WHITE: No. Their mandate requires hospitals to screen all infants and to report the results of that screening

to the state Department of Health. But it did not mandate follow-up.

PENNY HATCHER: Based on the fact that some of the data shows that hospitals are not, and that is a recommendation in helping them, what is that particular state's plan?

I mean, they went in to change the legislation for the one activity. I'm just curious because that is the situation here in Minnesota. We have no mandate at all. Some hospitals follow-up the babies and some don't.

KARL WHITE: Right. What this state did was to use the rule-making process to make mandatory reporting. They are a bit worried about opening up the legislation again because economic times took a turn for the worse and they are afraid that legislators might discontinue screening as a way to save money. So the plan now is to work with hospitals on a more voluntary basis for a while and see if they can impact it that way. If not, then I think they will revisit the legislation, but they are a bit concerned about doing that.

ELLEN FIORE: This is Ellen Fiore at March of Dimes in New York. I was wondering, are there any plans to put in place a long-term follow-up to follow the children who are identified by the universal newborn hearing screening to see, as they progress through school, their improvement in language skills over those perhaps from states that didn't have universal newborn hearing screening?

KARL WHITE: There is a plan in each of these three states to follow those children. Part of the data management tool is a registry of kids with hearing loss in which data can be continually updated and add to it. There isn't a plan right now to compare those with other children. The difficulty as you well know is finding an appropriate comparison group. But the data are certainly there for these children, which makes it a possibility to identify such a group. But nothing definitive in these states' minds about doing that right now.

ELLEN FIORE: Thank you.

THERESA: This is Theresa in Dallas.

The metabolic and genetic screening folks seem to have more effective follow-up than many of the nation's newborn hearing screening programs. Can you give us insight as to what you think they are doing differently than we are?

KARL WHITE: I think it's an evolutionary process, Terese. I think the reason it happens better with metabolic screening programs is that over the years physicians have become completely convinced that follow-up of metabolic screening is essential. So if they are notified that a baby has been referred from metabolic screening, things happen quickly. We haven't educated physicians to that point about newborn hearing screenings. So it's not unusual for a physician to respond that this is something that may or may not be serious and maybe we should wait a bit to see.

I think as that educational process moves forward, we will see better follow-up rates. In states with which I am familiar, I don't see that the actual process in terms of how people follow-up is any different for metabolic screening than for newborn hearing screening, except that metabolic screening follow-up programs tend to have more FTE assigned to them.

LEE ANN RAMSEY: Hold on. I hate to interrupt, but we have about 14 minutes and still two topics to cover. Is there any way we can save any additional comments for Dr. White until the very end? Would that be okay?

LEE ANN RAMSEY: Thank you. Were Wendy Jones and Rosalind able to log on?

WENDY JONES: I'm on.

LEE ANN RAMSEY: Thank you. Wendy is joining us from the National Center for Cultural Competence.

Wendy, you can go ahead.

WENDY JONES: Hello everyone. I am Wendy Jones of the National Center for Cultural Competence, a component of the Georgetown University Child Development Center. The mission of the National Center for Cultural Competence, better known as the NCCC, is to increase the capacity of healthcare and human service programs in their design, implementation, and evaluation of culturally and linguistically competent service systems. In order to fulfill our mission, the NCCC conducts a variety of activities, focusing on the provision of training, technical assistance and consultation; networking, linkages and information exchange; knowledge and product development and dissemination.

Particular emphasis is placed on policy development and assisting agencies with conducting cultural competence organizational self-assessments. Additional emphasis is placed on providing approaches to assist with the systematic incorporation of culturally competent values, policy, structure and practices within organizations.

The NCCC has a variety of Federal partners including the Division of Services for Children with Special Health Care Needs (CSHCN), Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA). For a complete listing of the NCCC's Federal partners visit the NCCC's website at: <http://gucdc.georgetown.edu/nccc>.

The NCCC has developed a series of Policy Briefs for our Federal Partners at the Bureau of Primary Health Care, Office of Minority and Women's Health. Currently Briefs 1 through 4 are available and can be downloaded from the web site listed above. In terms of the Policy Brief series:

- Policy Brief 1 offers a rationale for the provision of culturally competent care;
- Policy Brief 2 provides a legal and legislative mandate for the provision of language access services to families/consumers/ communities with Limited English proficiency;
- Policy Brief 3 focuses on using culturally competent approaches in research methodology with diverse populations; and
- Policy Brief 4 presents strategies for increasing community involvement and engagement through the use of culturally competent approaches with individuals and community groups from diverse backgrounds.

As previously stated the NCCC can be reached via website. We also receive requests for technical assistance, consultation, linkages to consultants, NCCC publications, and general information via email and toll-free number at cultural@georgetown.edu and 800-788-2066. The NCCC has a resource bank of approximately 2000 materials including videos, monographs, articles, books, and tapes that address a number of themes related to cultural competence, linguistic access, children with special health needs; SIDS/ID; health disparities, assessment tools, etc.

Additionally, the NCCC maintains a database of consultants with knowledge of the NCCC's conceptual framework and approach to cultural competence and expertise in a variety of areas. NCCC faculty often provide linkages to local, state or regional consultants that may be able to best meet the specific technical assistance needs of individuals, programs and organizations.

Lastly, it is important to note that the NCCC has a discrete scope of work under its Cooperative Agreement with the Maternal and Child Health Bureau. Technical assistance and related project activities are available to a variety of constituency groups as defined by the NCCC's Federal partners. A variety of collaborative activities can be made available to non-constituents, but require additional funding.

LEE ANN RAMSEY: Are there any questions or comments? Well, thank you, Wendy, very much for sharing that.

WENDY JONES: Thank you.

LEE ANN RAMSEY: Jennifer are you on the line?

JENNIFER HUTCHISON: Yes. I'm here. I'm an AUD candidate from Galluadet University, and I actually

wanted to thank you for the opportunity to share some information with you today. It's related to the research I conducted as an Au.D candidate at Gallaudet and relates to the universal newborn hearing screenings as well as the other topics mentioned today.

I'll try to summarize my research and the results. It was a small pilot project that was conducted, and the goal of the project was to obtain information on parents' perspectives related to the universal newborn hearing screenings. Specifically, we wanted to survey parents of children who passed the screening process to look and see what information they gained, what information they actually retained following the process, and basically what was the take-home message for this population of parents, again for children who passed the screening.

We conducted a survey, and some of the target information that we hoped to gain was to look at the family's awareness of the screening as well as the results, family's understanding of the process and the results, and the format for which information is being provided to these families.

We also gained demographic information through the survey. The subjects that we worked with were a group of families who were receiving follow-up medical treatment at a County health facility in Montgomery County, Maryland. And they were all families who delivered at three specific hospitals. A paper survey was developed to be administered to these families through the nurses that they were seeing. And some of the specific questions that they were asked were: Was their baby's hearing screened? Were they informed of the results? And how were they informed of the results? Also, they were asked if they understood the information provided to them.

Another critical element of this study was that based on the population of the families we worked with, we did develop the survey in both English and Spanish formats, and this element proved to be critical to the finding that we gathered. We focused on a specific group of families who all had come from the same hospital in Maryland. This specific hospital has had their screening program operating since 1996 and they do employ 3 to 4 full-time screening technicians. They provide a comprehensive literature packet about the screening process when families register at the hospital, and they are informed of the results of the screening through a result card that is left in the baby's basinet.

Based on the linguistic needs of the population that we researched, we inquired how they would communicate this information to any Hispanic families at the hospital. We were told that the result cards left in the basinet were provided in Spanish and some of the screening technicians were bilingual. There was no established process for necessarily distributing such Spanish materials, and we did learn that the UNHS literature provided at registration was only available in English.

When we looked at the survey results we looked at them across all of the families and then looked at them by dividing them based on the Spanish or English speaking families. 18 surveys were collected, and the most significant finding in general was that when we divided the survey responses based on English or Spanish speaking families, there was a noticeable difference in the responses.

For example, in response to the question "Was your baby's hearing screened?", 100 percent of the English speaking families said yes. While 69 percent of the Spanish speaking families actually replied that no, their baby's hearing was not screened or they were uncertain of the information. We saw a similar pattern in looking at a response to the question: Did they understand the information provided? 100 percent of the English speaking families we surveyed did respond yes, they understood. Only half of the Spanish speaking families that we surveyed understood the materials provided.

Overall, the survey responses did show a clear dichotomy between the English speaking families and the responses of the Spanish speaking families. Most significant perhaps was to note that 42 percent of the Spanish speaking families said their child's hearing was not screened. So based on the information that we obtained, it does seem to show that there is a need to address the services being delivered to the specific populations. Again, we did want to comment that the hospital had taken some steps to meet the specific population, they were lacking perhaps a

systematic or effective means for distributing the materials that they had started to use.

So, in conclusion, I would say that I think that the results of my survey, although it is a small population, do show a need to look at the quality of services especially for these ethnically and linguistically diverse populations that the UNHS and EHDI programs are servicing.

Thank you for the opportunity to share this information with you. Again, if you have any questions...

LEE ANN RAMSEY: Thank you. Are there any questions for Jennifer?

PENNY HATCHER: I'm from Minnesota. It's not really a question, but I'll pose it to CDC. Jennifer, is there a way you could write up a summary of this and somehow it can be posted at the CDC websites? Even though your sample size was small, I think any little bit, what you learned is helpful as we work on parent material. And so just some way we can capture and keep what you studied so we can look at it later and share with our colleagues.

JENNIFER HUTCHISON: I'd be happy to summarize these results. I'll share the results at the AAA convention. But if there is someone at the CDC, I'm sure I can work out a way to get this information available.

LEE ANN RAMSEY: Sure. We can contact you after the call, Jennifer, and figure out how best to do that. Any other questions or comments? Well, thank you each of our speakers. It is 3 o'clock on my clock. But I'm sure they won't cut us off. Irene? You had a question?

IRENE FORSMEN: I wanted to respond to Terese's question about the difference between the metabolic and EHDI screening programs. One of the major differences is with the metabolic screening program, the state health department assumes a lot of the responsibility for follow-up. It's not left to the hospitals. And my second point is that, unfortunately, there is a very long ugly history of litigation.

LEE ANN RAMSEY: Thanks, Irene. That concludes our program for today. Again, thank you, and happy new year for each of you and we look forward to the next call, which will be March 10. Have a good day.