

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Special Topics Teleconference
July 11, 2006**

Roughly Edited Transcript

**Overview and Results from the Colorado and
Massachusetts Family Survey Project**

DATE: July 11, 2006

TIME: 2:00pm (eastern)

Agenda

- I. Welcome
- II. Jessica MacNeil, MPH, Epidemiologist, Newborn Hearing Screening Program, Massachusetts Department of Public Health
- III. Vickie Thomson, M.A., State Audiology Consultant, Colorado Department of Public Health & Environment
- IV. Questions and Discussion

Comments

Marcus Gaffney (CDC-EHDI): Good afternoon everyone. On Today's call an overview and results from the Colorado and Massachusetts family survey project will be presented. Today's speakers include Jessica McNeal, who is with the Massachusetts Newborn Hearing Screening Program, Department of Public Health and Vickie Thomson, State Audiology Consultant with the Colorado Department of Public Health.

Jessica will be presenting first today. She's going to give you background on the project, so I won't go into any of that.

Jessica: Good afternoon, today I will be presenting the results of an evaluation project that we recently completed which looked at families' satisfaction with the Early Hearing Detection and Intervention services they received in Massachusetts and Colorado. Massachusetts, Colorado, and the CDC EHDI program collaborated in the development of this project and both Massachusetts and Colorado carried out pilot survey projects. I will briefly cover the background and protocol development slides and will then present Massachusetts' data. Vickie from Colorado will then present her results and we will have time for questions at the end.

The benefits of early identification of hearing loss in the areas of speech, language, and cognitive outcomes have been well documented and researched. And previous studies have evaluated the effects of newborn hearing screening and the diagnostic process on families. However, there has been little work addressing families' experiences with the comprehensive EHDI process. In order to address this

gap we, along with our study partners, developed a survey for states to use in evaluating the quality of EHDl services available in their state.

The primary objectives of this project were: to determine the levels of families' satisfaction and anxiety associated with the EHDl process; to determine what factors affect families satisfaction levels with the EHDl process; and to assess whether or not a child's hearing status affects the level of satisfaction.

Our partners in developing this project were the Colorado Infant Hearing Program and the CDC EHDl Program. Together we developed a detailed survey protocol along with the survey instruments and materials. We went through the IRB review process, and both MA and CO conducted pilot survey projects.

In order to carry out this evaluation project a number of products were developed. Invitation letters were created to be sent out with the survey instruments. Surveys were developed for each of the 3 study groups, which I will explain in more detail in a couple of slides. Both the invitation letters and surveys were then translated into Spanish, and also back translated to ensure regional cultural competency. Massachusetts developed Microsoft Access databases for each of the surveys for data entry and data management which were shared with Colorado. And, SAS programs were created for the data analyses.

A pool of questions from other studies was initially developed by the Family Issues Committee, and Massachusetts and Colorado, with technical assistance from CDC, selected and modified questions from this pool to address the project's objectives. Parents were directly involved in selecting the questions as well as survey development, and each state was able to add state-specific questions to the end of the surveys. Surveys were coded to allow linkage with the state's EHDl tracking system. This has allowed us to collect more detailed demographic information for the survey participants, as well as to validate survey responses and conduct more detailed analyses with the survey data.

Separate surveys were developed for each of these 3 study groups, and included only questions relevant to that families experiences. The three groups of families that were surveyed included: 1) families with a newborn who passed their initial hearing screening; 2) families whose infants did not pass their initial screening but subsequently passed on outpatient re-screening or diagnostic evaluation; and 3) families with infants who were identified with a permanent hearing loss.

Samples for groups 1 and 2 were randomly selected from all January 2004-July 2004 births. Racial and ethnic minorities were over-sampled to increase our statistical power for these groups during the analyses. The sample for Group 3 included all children born between January 2002 and April 2004 who had been diagnosed with a permanent hearing loss. The longer sampling period for this group was due to the smaller sample size we expected for this group.

Initially, MA sent 1,200 surveys for both Groups 1 and 2. However, because our data system is not able to differentiate between infants who are screened after transfer to a NICU outside of the birth hospital, and those that receive outpatient re-screens, approximately 2/3 of the surveys returned from group 2 parents reported that their infants had not been re-tested after hospital discharge, and they had passed the screening. Therefore we decided to include those surveys in group 1 and sent an additional 1,345 surveys to sample the rest of the families in group 2 to increase our sample size. In total we sent over 4,000 surveys and received more than 1,100 surveys back. Our final response rate for group 1 was 27%, for group 2 was 25%, and for group 3 was 34%.

To access families' satisfaction with newborn hearing screening services in Massachusetts each group was asked "overall how satisfied were you with the hearing screening services provided to you and your baby?" There was no statistical difference in responses between group one and group two, with 88% of families in Group 1 reporting that they were either very satisfied or satisfied and 86% of families in Group 2 reporting that they were either very satisfied or satisfied. Respondents in group 3 were less likely to be satisfied with 75% reporting they were either satisfied or very satisfied.

Parental anxiety associated with the hearing screening was addressed by assessing parental anxiety prior to screening, and anxiety post-screening. When asked, "How did you feel when you first learned that your baby would have his or her hearing screened?" respondents in group one reported being less anxious than group two or group three. Only 4% of group 1 respondents reported being anxious or very anxious while 15% of group two and 19% of group three respondents reported anxiety.

When asked, "When you learned the results of your baby's hearing screening, how did you feel," respondents in groups two and three reported increased anxiety compared to group 1. Only 1% of group 1 respondents reported anxiety after screening while 28% of group 2 and 43% of group 3 respondents reported anxiety.

Families with infants that did not pass their initial hearing screening, were asked to rate if "What you were told to do next was?" clear or unclear, 83% of families from group two and 90% of group three families reported it was clear what they needed to do next after screening. We feel this means that hospitals in MA are doing a good job making follow-up appointments and communicating information to parents.

Among those groups of families that required outpatient re-testing services, 97% of group two families reported they were satisfied with the re-testing services received compared to 87% of group three families who reported being satisfied with these services.

We also evaluated parents anxiety before re-testing, 35% of group 2 families and 46% of group 3 families reported anxiety when they first learned their baby's hearing would be re-tested.

When looking at parent's anxiety upon finding out the results of their babies outpatient hearing re-testing, 64% of families in group 3 reported anxiety while only 4% of group 2 families reported anxiety when learning the results of their babies outpatient hearing re-testing.

The next slide shows the time parents reported it took until the first re-testing appointment. Families in group 3 tended to report it taking longer to get a re-testing appointment than families in group 2. Eighty-seven percent of group two parents and 66% of group three parents reported that re-testing had occurred within one month. When asked to identify barriers to re-testing, the most frequently reported barriers were: that the hospital made the appointment but it was not convenient, it took too long to travel to the appointment, making telephone calls for the appointment was difficult, it was difficult to take time off work, and it was hard to find someone to care for other children while at the appointment.

The next slide shows the number of outpatient re-testing appointments parent's report attending before a diagnosis was reached. Eighty-eight percent of group two parents reported attending one re-testing appointment. For group three parents, 35% reported attending one appointment, 28% two appointments, 15% three appointments, and 22% more than three appointments. When asked the reason that more than one re-testing appointment was necessary, 21% of families in group three reported the baby was fussy, and 38% reported that the results were unclear or inconclusive.

93% of families with children with hearing loss reported they were very satisfied or satisfied with their audiologist's experience working with infants and young children. 94% of group 3 families reported they were either very satisfied or satisfied with the care and services their baby's audiologist was providing.

Parents with children with hearing loss were also asked if they felt the information they were given about intervention and communication options was equally presented. Sixty percent of families reported the information was unbiased, 19% the information was somewhat unbiased, 16% the information was somewhat biased, and five percent the information was very biased.

Sixty-four percent of families with children with hearing loss reported that after looking back at the activities involved in finding out that their child had a hearing loss, there were many more benefits than negatives. Twenty-seven percent reported that there were a few more benefits than negatives, seven percent that there were a few more negatives than benefits, and two percent that there were more negatives than benefits.

In MA all children with permanent hearing loss are eligible for EI services. Slightly more than 80% of families of children with a hearing loss reported that their child was receiving EI services. Based on previous program evaluations we know that approximately 75% of children with hearing loss in MA receive EI services.

70% of families reported they were very satisfied or satisfied with their early intervention program's knowledge of hearing loss and deafness. 79% reported they were very satisfied or satisfied with their baby's early intervention services overall.

Parents in all groups were asked if their baby's family members had a hearing loss that began during childhood. Nine percent of group one families, 15% of group two families, and 28% of group three families reported a family history of childhood hearing loss. Of group three families reporting a family history of childhood hearing loss, 42% reported multiple family members with hearing loss. When asked about whether their child had any health problems or special needs, 15% of families in group one, 18% of families in group two, and 27% of group three families reported health problems or special needs.

Parents in groups one and two were asked, "Were you informed that hearing loss can develop at any time and that concerns should be discussed with your doctor?" 39% of group one parents and 51% of group two parents responded that they were informed. So, there is a need for provider education around hearing loss in MA.

Next I wanted to share a few of the parents' concerns that were expressed when parents were given an opportunity to write in comments. The most common concern expressed among parents in groups 1 and 2 is that parents wanted to be present for screening. Comments from group 3 families included; "We live in a rural area and have to wait long periods of time to see audiologists and the ENT."; "We were given very mixed messages at the hospital at the time of screening, there needs to be improved training on how to talk with parents."; and "There needs to be more advocacy for insurance companies to cover at least some of the expenses for hearing aids."

Some of the positive feedback we received included; "Thank you for having the newborn hearing test. My son's result led to re-testing and enrolling in EI. Your process is working great."; "I am grateful for the screening program. My son only has hearing loss in one ear so if he was never screened we would not know he has a hearing loss and would have missed out on EI."; and "We wish all states approved this law. All babies deserve this early start."

In all three groups surveyed the overwhelming majority of families said that if they had another baby they would want him or her to have his or her hearing screened. We believe this shows strong support for the universal newborn hearing screening initiative in Massachusetts.

Additional topics that are covered in the survey which I have not presented results from include: parental knowledge and understanding of the EHDI process, timing and delivery of services and results, barriers to service, timing and receipt of information, and additional questions on satisfaction and parental attitudes toward screening.

I want to talk about some of the limitations of the survey. One, we definitely saw selection bias. Families that returned the surveys were demographically different than those who did not. In addition we suspect some recall bias. For some families it may have been a long time from when they received EHDI services and when they received our survey, which may have affected the results. In addition, for parents that have had more contact with the EHDI system or have a child with a hearing loss and have invested a lot in this system, that could also affect their recollection of events. Also, we have a lot of qualitative data and we need to determine how to analyze it most effectively. Finally, sample size became an issue for groups 2 and 3 when trying to conduct some of our analyses, especially when trying to break down by demographic groups.

A few of the lessons we have learned while carrying this pilot survey project include: to improve response rates, and also parents recall, surveys should be sent soon after birth. This project should be built as part of a program's evaluation activities to help avoid administrative delays. Finally, additional efforts are needed to increase participation among diverse groups – only 8.8% of Spanish surveys were returned.

In conclusion, we have determined that overall, families are satisfied with the EHDI services they receive in Massachusetts, that parents support universal newborn hearing screening, and that most children with permanent hearing losses are receiving EI services.

Our next steps include: developing manuscript for peer-reviewed publication, distributing surveys to other states, and utilizing survey feedback to improve our program and families' experience with EHDI in Massachusetts. I have enclosed our program contact information if you have questions later. With that I will turn it over to Vickie.

Vickie: Thank you. It was fascinating for me to see results from Massachusetts. This was the first time we have shared our results together, and how very similar the results were. It will be interesting to find the time over the summer to actually compare our survey results on a 1:1 question basis.

Most of you know, that's our fearless leader, Marion Downs, with Janet's daughter Sarah, one of our little guys, Ulie,. We disseminated 1500 surveys for survey 1 and 2, 400 for survey 3, and response rate was around 25% for both surveys 1 and 2. We sent out 240 surveys for survey 3 and received 83 .

, As Jessica mentioned, when we went so far back families had moved, quite a few were undeliverable. Next slide, when did you first learn your baby's hearing would be screened or needed to be. Over 80% prior to or at hospital admission. We were very pleased, concerned that families weren't getting results before leaving the hospital or weren't aware the baby had a potential hearing screen. -- To actually improve the knowledge of all newborn screens, Colorado has a task force to work with OBGYN's, and pass out information packets rather than have parents weed through information at time of delivery.

Next question, how do you feel when you heard your baby would have his or her hearing screened. Over 70% were not anxious -- how were you first told, 85% learned from staff or physician before they went home from the hospital. It was interesting that when asked the question whether they felt certain or likely their baby had a hearing loss 3% from survey 2 responded yes and , then it jumped to 35% from survey 3, Next slide. When you learned the baby needed further testing -- similar results again. Survey 2 and 3, down to 3, you can see a much higher percentage of families feeling averages anxious at that point. In all surveys parents responded at an average of 1.8. Very positive. Experience with the equipment, a definite yes or yes. Screening staff having a lot of experience, the test and explanations were done professional, explanations and answers to questions were clear rather than confusing, the majority said they were clear. What you were told to do next, clear. And just about right timing, and suggestions listened to. That was real positive. Overall, how satisfied were you with services provided? Ranged from 85% to survey 1, being very satisfied or satisfied, to 76% for survey 3, similar to Massachusetts.

Did you have problems getting out-patient retesting -- the concerns noted on our surveys were difficulty with transportation, and that stems from being a rural state, we have a number of families who do not have the transportation available to even get back to the hospital, because the hospital may be several hundred miles away or getting to an audiologist for a follow-up rescreen, and daycare for the other children was a top concern.

For the out-patient rescreen, how long did it take to get a rescreen appointment, 85% were able to get one within the first month. How many times did it take for your out-patient retesting, Similar to Massachusetts I found it disconcerting that several families stated it took more than three times. In Colorado, our guidelines try to encourage, if you have an unsuccessful attempt or baby does not test at the out-patient rescreen the family needs to be immediately to obtain a referral for an audiological

evaluation--. Something we are definitely going to be working on.

At this point 41% of the parents were pretty convinced their child had a hearing loss. Over 85% were satisfied or very satisfied with the staff performing the out-patient rescreen.

Once they got into audiology 85% are satisfied with their audiologist. 85% of families felt the communication options given to them were very unbiased or unbiased. Same with Massachusetts, interesting, reporting of family history of hearing loss, only 8% in 1, and 20% in survey 3. A question about how they felt the baby's health was, excellent to poor. 84% in survey 1 thought their baby's health was excellent to 48% in survey 3. A very large decrease in the perception of baby's health between survey 1 and 3. Survey 1 respondents reported that 8% of their children had special needs, and Survey 3 reported 47%. Another area I want to go back and look at more. What parents report that special need is .. Its, -- 88% thought there were benefits to screening. Similar to Massachusetts, those whose infants passed new born hearing screening, only 50% were aware that hearing loss could occur later -- reporting early intervention services, 50% reporting of wear hearing amplification. We will need to go back and look at individual surveys themselves to see if a large percentage of surveys were infants with unilateral versus bi-lateral. It was a little interesting, actually upsetting to me.

Several parents reported they did not just want to be given a card, letter in the crib, when a baby failed a screen. There should have been some face-to-face contact with someone who understands the system. Some wanted immediate contact with family support. In Colorado that would be Hands and Voices. All families should have access to hearing aids, not just families with Medicaid. Most insurance companies do not pay for hearing aids, only those children -- are guaranteed amplification, and as a result we have implemented a hearing aid loan bank, only Band-Aid -- probably shouldn't say that on air. My physician told me not to go back for a rescreen since this test is-- designed to scare parents. Several parents made that comment. The shows the need to emphasize education, the importance of getting children back for the rescreen. Our chapter champion, doctor Dr. Mehl-- has been wonderful in helping with that.

Overall we found the surveys are very useful.

Looking at which questions are redundant, it's a long survey. The survey should be disseminated within six months of diagnosis CO is working with NCHAM in -- developing screening training materials. It's so critical families get the right message consistently from screeners about follow-up, for hearing loss. Continually providing additional training for audiologist to increase the number of audiologist who can provide services, have the equipment, and experience and who can provide-- the diagnosis for families.

My partner in crime, really helped me a lot with this analysis, Janet DesGeorges, worked with me on the whole survey project., Parents really are the most critical part to our EHDI system, without the input of Hands and vVices we would not have the current system we have now. With that, I am finished and we can entertain questions.

Question: Did you both submit IRB's, great evaluation tools, but I question how much time it takes if we were to do this on Annual basis if we had to go through IRB.

Answer: I went through the initial IRB process. And the people in IRB felt it really was an evaluation tool. We included some of our questions, use a PRAMS data set, going to all moms -- shouldn't say all, but a select set of mothers. We did not have trouble. They have applauded our willingness to want to evaluate the program.

In Massachusetts, CDC waived the IRB through their program because it was -- situation and because of that we were able to pretty easily get it through our own IRB approval and through the legal office.

Vickie: Another thing to consider, especially for those of you in Title 5 programs, one of the MCHB National Performance outcomes in parent satisfaction for the services provided, ties in nicely with our goals and objectives for obtaining parent satisfaction.

Marcus: On the CDC-EHDI website (<http://www.cdc.gov/ncbddd/ehdi/research.htm#evaluation>), you can actually download PDF copies of the surveys we used in the project,

I also wanted to point out both Massachusetts and Colorado did an incredible amount of work on this project. Did an incredible job and worked very hard to complete the project.

Vickie: I would like to thank CDC, it was great working with them, helping us think through what needed to be done in terms of the IRB, questions, and Vickie with Massachusetts, it was a great project. More to do.

Jennifer: We feel the same way. I wanted to add, we sent an annual report this year. It was a way for us to let our -- stakeholders, audiologists, hospitals know how families feel about the services. We have also had a opportunity at a few different conferences for presentations to be able to go present, and I think people really appreciate getting that feedback. I know our audiologists are very happy to hear about the high rate of satisfaction, and our advisory committee was very pleased, the work they have been helping us do all these years, they felt families were really quite satisfied with the services. I think it can be used for a lot of different audiences, go through the whole process of doing surveys, analyzing data, and then it really gives you good ideas about how to continue ongoing evaluation with the program to ensure the results continue. We are particularly interested in group 3, families with children diagnosed with hearing loss and trying to figure other ways to also work with the survey to make sure we are meeting those family's needs.

Marcus: If there's nothing else, again, a big thank you to the speakers and to everyone for calling in. Next special topic on September 12, also at 2 pm. Information on the topic of that call will be sent out closer to the date. I wish everyone a great afternoon.