Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
January 7, 2003

TO: Ad Hoc Group for EHDI
FROM: CDC EHDI Program
SUBJECT: Conference call-in number and agenda.
DATE: January 7, 2003

The next EHDI teleconference will be on Tuesday, **January 7, 2003** from 2:00 to 3:00 pm **Eastern** time. To join in please call: **1-800-311-3437**. You will be greeted by an automated voice and asked to enter a CONFERENCE CODE. Dial **Code 796649.** Federal participants may call *404-639-3277***.** Please call in 5 - 10 minutes before the conference starts so we can begin promptly at two. If you have any questions please contact Marcia Victor *(MVictor@cdc.gov /*404-498-3035*)* or 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 as soon possible.

Agenda

I. Welcome and announcements

II. Update on cochlear implant / meningitis investigation
– Jennita Reefhuis

III. Using Part C of IDEA to Support Statewide EHDI Programs
- Karl White
(http://www.infanthearing.org/checkpoint/cdc/slideshow/800x600/slide1.html)

CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE
January 7, 2002 2:00pm (eastern)

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Krista Biernath: Good afternoon. This is Krista from CDC, and I'd like to welcome all of you to this month's early hearing detection and intervention ad hoc teleconference. I guess we'll go ahead and get started.

Before we start, though, I'd like to remind you to please mute your telephones when you're not speaking and this will help reduce the amount of background noise. Today's conference is being recorded, and the transcript will be provided on our website.

A few announcements. First, I want to thank you to everyone who sent suggestions for teleconference topics and speakers last November. We've had a really good response to that request, with many good suggestions, and we have already used one of these suggestions for today's teleconference, and we plan to use more for more of the conferences.

Second -- our second speaker today, Karl White, will be using slides, and these are posted on the NCHAM website. If you have not already downloaded them or you're going to be using them during the presentation, the link can be found on the e-mail that was sent out yesterday to all listed participants. Does anyone have any other announcements?

Okay. Our first speaker today is Jennita Reefhuis and she's an EIS officer from CDC. She's the lead investigator on the cochlear implant/meningitis FEA that CDC is conducting and Jennita will be giving us an update on the investigation.

JENNITA REEFHUIS: Okay. Thanks. Hi, everybody. I'm going to give a brief update on what we've been doing so far. I would ask you to keep any questions until the end of the presentation. There will be time to ask questions. However, one of my vices is that I talk too fast so if that's the case, feel free to interrupt me and tell me to slow down.

But that said, I would like to get started. As Krista said, I'll be talking about the public health response that CDC is doing together with many other people, looking at risk factors for bacterial meningitis in U.S. cochlear implant recipients under age 6 at the time of the implant. This is a large collaborative effort, first of all, with Krista and me and many other people from the National Center on Birth Defects and Developmental Disabilities at the CDC, but also CDC's National Center of Infectious Diseases are involved, and the National Immunization Program is also involved because of course there are also immunization issues with this topic. And from the states, the state epidemiologists and other staff at many state and local health departments and of course as some of you know, EHDI programs in some states have collaborated with us in this investigation. And in addition, we have several people involved from the Food and Drug Administration who initiated and have collaborated in this investigation.

The public health response questions that we are trying to answer is whether, among children who received cochlear implants, whether the risk of meningitis varies by, for instance, a history

of otitis media, a history of meningitis prior to the implant, the device type, which of course is one of the reasons we started this investigation, but also possibly ear malformations, children who have certain types of ear malformations might already be at an increased risk for meningitis compared to children who do not.

Also, we're looking at, for instance, vaccination history and the age at implant, which is also a topic that has -- that has been in our minds because the age at implant has decreased over time. The way that we're doing this investigation is that we designed a case control study. Cases and controls are restricted to cochlear implant recipients who received their implant on or after January 1st, 1997, and before August 31st of 2002.

Also, we had the requirement that the child had to be less than six years of age at the time of the implant. We selected the controls as a stratified random selection of all children who received implants before age six since 1997. The three companies who are licensed to market cochlear implants in the U.S. sent us the lists of all children that they know to have received an implant, and we used that as our study population to use -- to select our controls from. And in addition to the cases and the controls, as a case finding strategy, we did a lot of case finding because we wanted to be sure that we had all cases in the U.S. We contacted -- used the information that the companies sent us to contact all parents of children who had a cochlear implant in our time period, and asked if their child had had a serious illness since the implant. And that way, we were hoping to receive additional cases -- information on additional cases of meningitis. And we also contacted states and we asked the states if they had any reports of children with meningitis who were also cochlear implant recipients, to notify us. In addition, we contacted audiologists to ask them the same question, and we used databases and surveillance systems that were already in place at CDC, and at the FDA. So we did -- we really tried very hard to know about all of the cases of meningitis that were diagnosed in the U.S. among recipients of cochlear implants.

Before the cases and the controls, we did data collection on several different -- using several different methods. First of all, we did a medical record abstraction of the implant hospitalization. We went back to the hospital where the child received the cochlear implant and we developed an abstraction form that contained questions specific to the surgery, such as were antibiotics used during or before the surgery, was there a complete insertion of the electrode, things that really pertain to the -- to the surgery itself. And so we tried to do implant abstractions for all cases and controls and that's definitely something that EHDI groups and state-based people helped us out with a lot, because as you can imagine, cases and controls in 35 states and we couldn't travel to each and every one of those locations, since there were very often multiple hospitals even within one state.

To abstract the medical records for the cases of meningitis, we went to the hospital where the child was diagnosed with meningitis, and we did an abstraction that contained questions basically to ascertain that it was truly a case of bacterial meningitis and definitely also trying to find out what was the cause of meningitis. Was it streptococcus pneumonia or was it hemophilus influenza or another type. In addition, we contacted the parents and tried to interview parents of all cases and controls. We did this by using 16 Atlanta-based interviewers who called the parents and did an interview that took approximately 15-minutes. For parents of children who had had meningitis, the interview was longer because there were questions about the episodes of meningitis. During the parental interview, we basically asked questions about the cause of meningitis, the history of otitis media, for instance, and things like that.

And the last source that we used were primary care providers. Not only did we ask for the immunization records of these children but we also asked for a brief medical history information.

As I briefly mentioned before, we did the case finding where we sent it out to all the parents of children who were not cases and who were not selected as controls. The response to that was quite impressive, I think. We had 2% that was returned as undeliverable, which I think is a severe underestimation because those are the ones that are actually put back into the mailbox and sent back to us. I think most people, if it's not for them, they'll just toss it in the trash. So that was 2%. And 56.6% of the forms that we sent out were returned with the necessary information, and I think for something that you just mail out to people who possibly -- we have 7-year-old addresses for – I think was -- or 5-year-old addresses -- was quite good. And 7.1% of those, of the 56.6%, indicated that their child had had a serious illness.

The serious illness varied from infections that they had related to the surgery to having been diagnosed with diabetes, but it did result in additional cases of meningitis. There were parents that indicated that their child had had meningitis since that we were not aware of yet. So we -- we identified a total of 8 additional cases, 4 through these forms, and in addition to the forms, people could also give us a call instead of sending the form back. So 3 people called after they received our letter to indicate their child had had meningitis. And 1 additional case came in through the FDA's med watch system. This is a system that the FDA maintains which people can notify the FDA of any side effects or diseases in people who have, for instance, cochlear implants but also if they have been taking a particular drug. So we had that -- one additional case as well. So we had a total of 31 initial cases of meningitis that we started to work with.

After the people from NCID, from the National Center for Infectious Diseases, reviewed those, four were determined not to be true cases of meningitis. But had other diseases. So we had a total of 27 cases of bacterial meningitis.

So the data collection, how well did we do with those? Of the controls, 81% was interviewed, and for the cases, this was 96%, so this is pretty good. The implant abstraction was better definitely for the controls. We had a 93% completeness for the implant abstraction for the controls, and a 93% as well for the cases, and also a 93% abstraction for the meningitis hospitalization for the cases. And for the primary care provider, we had 80% for the controls and about 74% for the cases. So I think overall, we had a pretty good response rate, and there's a lot of information available right now.

We're collecting all the information and as you can imagine, there's information from different sources that we now have to combine into one database.) So that's the situation that we're in right now, and what we're working hard on to get it finished. And hopefully, soon, within the next couple of months, there will be a -- a publication ready and -- and as that appears, I'm sure that Krista will inform you of -- of the location of that publication. I would like to leave it at that. I'm very happy to answer any questions anybody might have. Are there any questions?

Krista Biernath: Jennita, did you mention about when you think the results will be out or do you have any idea of that yet?

JENNITA REEFHUIS: I said a couple of months.

Krista Biernath: Just to let the participants know, if you go on our website, there is a cochlear implant portion of our website that you can watch, and as soon as the results are published, we

will provide that information that it has been published and where to find it.

Are there any other questions for Jennita? Okay. Well, thank you very much, gentleman neat A that was really interesting. And what we'd like to do now is to go to our next speaker. I do want to remind everybody once again to please mute your phones. There seems to be a lot of feedback on today's call. I'm not sure where that's coming from. But that would be really helpful if you could do that. Thanks.

Our next speaker is Karl White from the National Center for Hearing Assessment and Management, or NCHAM, at Utah State University, and he will be speaking on using Part C of IDEA to support statewide EHDI programs. I would like to mention that this presentation was suggested by one of our teleconference participants, and so I just want to say that we're very grateful for that suggestion, and Karl, are you on?

KARL WHITE: Thank you, Krista. As mentioned earlier, slides that accompany my presentation are available on our website at http://www.infanthearing.org. I will discuss how Part C of IDEA (Individuals with Disabilities Education Act) can be used to improve statewide EHDI (Early Hearing Detection and Intervention) programs. To set a context for that topic, it is important to remind ourselves of how rapidly newborn hearing screening programs have increased over the last decade

As shown on slide #2, by January, 2002 we were screening approximately 70% of all newborns in this country. I estimate that we are probably screening 80 or 85% now.

As shown on slide #3, 37 states have passed legislation related to universal newborn hearing screening. That legislation, along with federal support, has led to the implementation of statewide EHDI programs in every state in the country.

As the implementation of statewide EHDI programs has progressed, it has become very clear that you can't implement a successful EDHI program without the assistance and cooperation of lots of other people. One of the most important resources available to assist with EHDI programs is Part C of the Individuals with Disabilities Act (IDEA), which was passed by Congress in 1997. IDEA is a continuation of the Education for Handicapped Children's Act passed in the mid 1970's --- often referred to as the mainstreaming law. Part C of IDEA provides federal funding to assist states in providing early intervention services to children from birth through 36 months of age --- including those with hearing loss.

As shown on slide #4, the purpose of IDEA is to provide financial assistance to states to assist them in implementing statewide early intervention programs for infants and toddlers with disabilities and their families. The wording "financial assistance" is important because it underscores the fact that the majority of funding for each state's early intervention program is really state money. The federal money assists, but it is a relatively small portion of the total amount required.

All states and territories are participating in Part C of IDEA and have created publicly funded early intervention programs. As shown in the excerpt from the law on Slide #5, in order to receive federal funding, the state has to commit to make appropriate early intervention services to ALL infants and toddlers with disabilities in the state.

They also must agree to develop a statewide system that includes at least the components

listed on slide #6. Several of these components are particularly relevant to the operation of a successful EDHI program. For example, each state must define the criteria whereby infants and toddlers, including those with hearing loss, become eligible for the Part C program. Other components that are particularly relevant to EDHI include those dealing with child find, multidisciplinary evaluation, public awareness, and central information directory.

Before talking about some of these individual components in more detail, it is important to remember that many of today's early intervention programs that are funded by Part C (and her predecessors) have been in place for over 25 years. Back then, most of the children with congenital hearing loss who were identified before they were three years old were those with severe or profound bilateral losses. Not surprisingly then, most of our current Part C-funded early intervention programs for infants and toddlers with hearing loss are designed to serve children with severe or profound losses. Now that we have so many newborn hearing screening programs though, the majority of children being identified with congenital hearing loss have mild, moderate, or unilateral losses. Thus, many, if not most, of the existing Part C programs are not designed to serve the majority of children being identified with hearing loss --- those with mild, moderate, and unilateral losses. That means that many Part C programs will have to be re-designed to some degree to be appropriate for most of the infants and toddlers being referred to them. Such re-design will happen most efficiently if it is done in close cooperation with those who are responsible for the implementation of EDHI programs.

The information at the bottom of slide #7, shows that we still have a lot of work to do to make sure infants and toddlers with hearing loss are enrolled in early intervention programs as early as they should be. Each year, our center surveys the state EHDI coordinators to learn more about the status of EDHI programs in the states. In January of 2002 we asked state EHDI coordinators to estimate how successful they were in getting infants who had been identified with hearing loss enrolled in early intervention programs. They indicated that only about 53% of the infants who had been identified with hearing loss were being enrolled in appropriate early intervention programs before six months of age.

According to the Joint Committee on Infant Hearing, MCHB, and CDC all infants and toddlers with congenital hearing loss should be enrolled in early intervention programs **before** six months of age. Yet, according to state EHDI coordinators, we are achieving this goal only about half the time. So there still is a lot of work to be done just in terms of getting children enrolled in programs.

We also asked state EHDI coordinators to indicate whether parents had an adequate range of choices for early intervention programs. As you probably know, there are many different communication options for children with hearing loss ---for example, total communication, American Sign Language, auditory-oral, cued speech. Parents often have very strong preferences about which communication option they would like their child to use. Unfortunately, these data suggest that in most parts of the country, parents have limited options in selecting an early intervention program that uses the communications option they would like for their child.

A shown on slide #8, the Federal regulations that accompany IDEA require that states define eligibility criteria for participating in early intervention programs for at least two groups of children:

1. Those who are experiencing developmental delays as measured by objective instruments
2. Those who have a diagnosed physical or mental condition which has a high probability

of resulting in a developmental delay.

Of course, the vast majority of infants and toddlers who are identified with hearing loss will not exhibit enough of a developmental delay on these objective instruments to qualify for services until they are 12 to 18 months of age. This is not because the delays are not present. Instead it is because available instruments are not sensitive enough to measure those delays. Yet, these early months are an extremely important time for infants with hearing loss to be participating in early intervention programs. Therefore, it is extremely important that each state's criteria for children with these pre-existing conditions include infants with hearing loss.

Now, even though the federal statute requires states to serve infants and toddlers who "have a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay," states decide how they will define the criteria for that category. In other words, eligibility can be defined very narrowly or very broadly. By law, each state is required to document these criteria in writing in a "State Plan" that must be filed with the Federal Office of Special Education Programs (OSEP). To determine how states have defined eligibility criteria for infants and toddlers with hearing loss, we obtained a copy of the relevant section of each state plan from OSEP and did an analysis of the eligibility criteria.

Based on our analysis of these state plans, as shown on slide #9, we found, not surprisingly that all 55 states and territories indicated that early intervention services would be available to children who had a diagnosed physical condition with a high probability resulting in developmental delay. However, only 38 of those 55 -- or 71% -- listed hearing loss or something similar (such as auditory impairment or deafness), as one of the specific conditions that would qualify a child as having a condition with a high probability of resulting in developmental delay, and thus be eligible for services.

This means that for at least 17 of the 55 states and territories, a child with hearing loss would not be eligible for early intervention services in Part C programs unless they were exhibiting a substantial developmental delay, which is highly unlikely for very young children with hearing loss. However there is strong evidence to show that if these children do not receive early intervention services when they are 0-18 months of age, they will become delayed later and that those delays often have life-long negative consequences.

We also found that of those 38 states and territories that said they would provide services to a child with hearing loss as a pre-existing condition, only 7 provided any kind of an operational definition in the state plan as to what constituted a sufficient hearing loss to be eligible for services. In other words, would they consider a unilateral loss sufficient reason to provide services? Or a mild bilateral loss? Or a temporary ear infection that results in a mild hearing loss? Most states are probably not planning to provide services to all of these mild or even temporary hearing losses. Yet, without an operational definition of some kind, parents and policy makers have no idea about which children would be eligible for services and which would not be eligible. We did find that five other states had some type of an operational definition in other documentation outside the state plan, bringing to 12 the number with some sort of operational definition. However, one wonders why these eligibility criteria were not included in the state plan, which is the legally binding document for Part C eligibility.

The important information on slide #10 is the website address at the top of the page which shows you where you can find the summary we prepared showing the information from the 55 states and territories on what the operational definitions were and to what degree states provide

services to children with hearing loss. For each state we have excerpted the exact language from the state plan that pertains to children with hearing loss. This document is still in draft form. Last month we sent a copy of the draft to all state Part C Coordinators and asked them to double-check what we had written and to also provide us with any other information they had about eligibility criteria or procedures for children with hearing loss. But even in draft from, this document is a very useful resource for you to use in working with your state Part C coordinator to develop and/or refine the eligibility criteria for children with hearing loss to receive services under Part C.

To help clarify which children with hearing loss would be eligible for early intervention services, we asked the Part C Coordinators to tell us which of 5 hypothetical children with different types of hearing loss as shown in Slide #11 would be eligible for services in their state. In each case, we asked them to rate hypothetical children who were six months old, who don't yet exhibit any developmental delays, and who come from upper middle class two-parent families. The reason we added the part about upper middle class two-parent families is that some states provide services to children who are low SES or who come from single-parent families completely independent of whether they have a hearing loss or not, so we wanted to remove that variable from the rating.

Slide #12 shows the responses we've had so far from state Part C Coordinators. At least for those states who have responded so far -- and we anticipate having responses from the other states by the end of this month -- almost everyone said they would provide services to a child with a bilateral profound hearing loss. Only 61% said they would provide services to a child with a profound unilateral loss, and 22% said they would even provide services to a child with mild fluctuating conductive losses. This kind of information can be very useful as you begin to work with these Part C coordinators in deciding the kinds of services that will be available to children with hearing loss who are identified in your state.

As shown in Slide #13, the IDEA regulations also require each participating state to implement a comprehensive child find system. The regulations for the Part C child find system are very relevant to what we're trying to do with EHDI programs. The information on Slides #13 and #14 are quoted verbatim from the Part C regulations. As you can see, these regulations specify that the state is required to put into place a system whereby if a child is suspected of having a disability of any kind, a referral is made to someone who can conduct a diagnostic assessment of that child within two working days. Following this referral, the state is required to ensure that a diagnostic assessment is completed and an Individual Family Service Plan (IFSP) is implemented within 45 days.

It is important to note that the law requires the Part C agency or what is known as the lead agency (in about 1/3 of the states this is education, in about 1/3 it is health, and in about 1/3 it is social services or some other agency) is responsible to ensure that an appropriate system exists. It doesn't say that the lead agency has to do it themselves --- just that they have to ensure that it is happening. In most states, the Part C agency is relying on the EHDI system for these activities. But, this really needs to be a joint responsibility where the EHDI system is working hand in hand with the Part C agency to ensure that these federal guidelines are being met.

In addition to meeting the legal requirements for the system, we need to make sure these assessments are happening as quickly as possible because these babies need to be involved in early intervention programs and fitted with appropriate amplification as soon as possible. Both

the Part C and the EDHI program will be more effective in meeting this goal if they work together.

The guideline that CDC and MCHB have established is that all infants referred from newborn hearing screening programs should complete a diagnostic assessment before three months of age. The Part C guideline requires the diagnostic evaluation to be completed much earlier. According to Part C, the diagnostic assessment should be completed within 45 days from the time the referral is made --- in most cases this would be by the time the child is 1 ½ months of age.

Slide #15 shows the percentage of all birth to 36 month old children who are being served in Part C programs. That percentage has increased from about 1.2% in the early '90s up to 1.8% as of 1999/2000 (the most recent data available from OSEP). This is important because it provides information about the context in which Part C programs are operating. Remember, federal money only accounts for a small portion of the total cost of these programs. With the combination of federal money and state money, Part C programs are currently providing services to about 2% of the 0-36 month population.

As shown on slide # 16, about 205,000 infants and toddlers are currently being served in Part C programs. The incidence of hearing loss is about 3 per 1000. That means there are about 12,000 babies born each year with congenital hearing loss. Since Part C serves children from birth to 36 months of age, this means that at any point in time, about 36,000 infants and toddlers with hearing loss need services.

If we optimistically assume that about a third of these children, those with profound bilateral loss, were being served prior to the advent of newborn hearing screening programs, that would mean that another 24,000 children would have to picked up by the Part C program as soon as universal newborn hearing screening programs are fully implemented. 24,000 additional children represents almost a 12% increase in the number of children in Part C programs. That is a very substantial increase with no additional funding from the federal government. So, as we expand newborn hearing screening programs it is important to realize that Part C programs don't have unlimited money to serve additional children. Thus, it will be very challenging for Part C programs to respond to the increased number of infants and toddlers who will be attending these programs as a result of successful EHDI programs. Figuring out how to serve these children with no additional funding will have to be worked out very carefully and with a lot of give-and-take on how to provide appropriate services.

Finding ways to expand services even though there is no more funding is also relevant to the comprehensive multidisciplinary evaluation that Part C is required to make sure is available to these children. As shown on Slide #17, almost all children who are currently referred for evaluation in Part C programs qualify for those programs. But that is certainly not the case for newborn hearing screening programs. In existing statewide EHDI programs about 1% of all children born are referred for a diagnostic audiological evaluation, and only about 30% of these children will be diagnosed with a hearing loss. The number of diagnostic evaluations that will have to be conducted when EHDI programs become fully operational represents about a 50% increase over what Part C is now doing. What that really means is that Part C programs don't have the resources or the personnel in most cases to just assume responsibility for conducting multidisciplinary evaluations for children suspected of having hearing loss. Because of that, EHDI program staff will almost always have to be very deeply involved in making sure that those evaluations take place. However, the Part C program should be involved to some degree

because they do have a legal mandate to make sure these diagnostic assessments are being done appropriately.

One area where Part C programs might be helpful is in helping to pay for diagnostic assessments when parents are unable to do so. As shown in Slide #18, we presented the following hypothetical situation to Part C coordinators, "Assume you've got an infant or toddler who was referred to your Part C program from a hospital-based newborn hearing screening program as needing a diagnostic evaluation. Further assume that the child is not eligible for Medicaid and that the family has no health insurance. Would your Part C program pay for that service, not pay for that service, or some other stipulation?"

As you can see from that slide, 84% of the Part C coordinators said that in such a circumstance, they would pay for the diagnostic evaluation. So Part C is one of the alternatives available to assist with funding for these diagnostic evaluations, but it is important do remember that it is a limited amount of money.

For those of you who weren't familiar at all with Part C of IDEA, I hope this presentation has given you a little bit of background on what it is and how it functions. If you go to our website at www.infanthearing.org and click on "early intervention" there's some additional information there. We have posted the actual law and regulations, and some issue papers that have been written by various groups. Also, you can go to your state home pages that we've developed on our website and it will give you the information about who the Part C coordinator is in your state. If you are not acquainted with that person, he or she is someone you should get to know.

Beyond that, there are three “take home messages listed on Slide #19. First, cooperation between EHDI and Part C has important benefits for both groups. Part C is under federal regulation and law to provide services to these children. The EHDI programs are the ones with the expertise on how to do that most effectively.

Second, Part C isn't the pot of gold at the end of the rainbow. Even though states are mandated to provide appropriate early intervention services to all children with disabilities, there is a very limited amount of money and Part C budgets are already stretched to the breaking point. But even though there is very limited money, Part C does have an infrastructure and other resources that can be very useful to EHDI programs. We need to explore how that can be done more effectively.

Finally, the collaboration between EHDI and Part C may look easy, but it is not. It sounds so simple when you talk about it with a set of slides like this, but actually, it's a very complex undertaking when you get into the details. Something as simple as deciding which children with hearing loss qualify for Part C services, as you will see if you go to our website on that summary of eligibility requirements, becomes a fairly difficult thing to do. But, by looking at what other people have done, you will hopefully be better able to develop a plan that will be most effective for your situation.

If there are any questions, I would be happy to try to answer them.

Debbie Beringer: Karl, this is Debbie Beringer from the state of Michigan and I just have a question. We have the concept of the AAP chapter champions with the EHDI program and the pediatricians. Is there any thought about developing a concept similar to that to work with the Department of Education?

KARL WHITE: I think the Chapter Champion idea being used by AAP is tremendous, Debbie. But I think there is another infrastructure in place right now that could be used just as effectively, if not more so, to promote collaboration between EDHI and Part C programs. The law requires that each state establish a state Interagency Coordinating Council. These councils consist of 10 to 25 people representing various stakeholders in the Early Intervention process. It would make great sense for the EHDI coordinator in each state to volunteer to be on that council if they aren't already. From that position, they could do many of the same kinds of things that the AAP chapter champions are trying to accomplish.

VICKIE THOMSON: Are you suggesting or thinking -- and this is what we're struggling with -- is that infants should be referred to Part C at the time of referral on a screen?

KARL WHITE: No, no. See -- at least that's my opinion. That's not the way that I would do it because I think it would overload their system.

VICKIE THOMSON: Absolutely, yes. That's what we're thinking, too. So it ends up kind of being at the time of diagnosis, then the diagnosing audiologist and, well, in our situation, we have the (inaudible) will link to Part C, so assure that all those services take place.

KARL WHITE: Yes. It will be different in every state. The Part C regulations require the Part C lead agency in each state to have a system that will successfully accomplish the objectives outlined by the law, including timely evaluation. They may designate this responsibility to the state EDHI program, but the lead agency remains legally responsible under the law to make sure it is working effectively. Furthermore, even if this responsibility is designated elsewhere, it makes sense for the designee to take advantage of both the resources and the infrastructure that exists in Part C to accomplish there work. I think it makes sense that at the time that the child is referred for a diagnostic evaluation, to have them referred to the Part C program so that the child can be included in the Part C monitoring system. For example, whenever a child is referred to the Part C program, Part C is required to assign a services coordinator. That services coordinator could be instrumental in helping the family to receive the services they need.

UNKOWN SPEARKER: I wanted just to make a comment about the multidisciplinary evaluation, and I think this is true for most states, is that a multidisciplinary evaluation means an evaluation by a PT, OT, maybe visual screening and that kind of thing, and one of the things that we're struggling with, and I think all of us will, is that Part C has typically been seeing older children, so a developmental pediatrician may be skilled in an older child (inaudible) not be skilled in working with infants. That's just something we need to be cautious about because we've had children (inaudible) evaluations (inaudible) noise makers and then ended up passing (inaudible) screens that they had failed at the hospital and later diagnosed with significant sensory neural hearing loss. So I agree with you totally that we need to make sure we're involved in the Part C system and make sure that infants do receive appropriate services.

KARL WHITE: Yes. And there's a huge educational effort here, isn't there? This educational effort needs to address the needs of primary care providers, audiologists, early intervention providers, and parents. We are a long ways from seeing the light at the end of that tunnel.

VICKIE THOMSON: I would also suggest that along with the interagency coordinating council, that the state Part C coordinator be a part of everyone's advisory committee, if they're not already.

KARL WHITE: That's a great suggestion, Vickie.

BRENDA BLEDOSE: This is Brenda Bledsoe in Tennessee. I am the Part C coordinator, and I'm calling -- I'm on the call on behalf of our EHDI coordinator today. She had something else that was up. And we have worked very closely on this. I think some of the questions we're posing are things that we are trying to work through, and we have kept -- right now -- and I just got my survey mailed back together, so I apologize. But I've also sent you some of our draft forms for how we're going to collaborate on this -- the front-end part of that, and we're right now keeping the process of the child find process through the screening until we actually get -- there will be two screens before the child leaves the hospital, and then we will assist the EHDI project in any way we can with getting the family to an audiologist for a third follow-up after they leave the hospital, and we're keeping that as child find under Part C before we actually take it as a referral. We will take it as a referral when there is actually an audiological statement that the child does have a hearing loss. So this has been a real good working relationship in Tennessee, I think.

KARL WHITE: And I think that is the essence of what needs to be happening around the country….and it is gradually beginning to happen. But the exact way in which it's worked out will probably be different in all 55 states and territories. As long as people are talking with each other and getting down to the nitty-gritty details, then it will be mutually beneficial for everyone.

BRENDA BLEDOSE: Right. And I think that -- I guess what my main message here is, we're not sure that the things that we have are going to be, you know, tried and true, but we intend to make this work and so we'll try what we have. If that doesn't, we'll change it and update it as we go. But I think we have something very positive going.

BEPPIE SHAPIRO: This is Beppie, and I appreciate this presentation a lot, by the way, but I wanted to say that an important group to bring to the table in these discussions is the office of special education programs at the federal level, which monitors Part C performance, including child find, in the states, and has found many states not in compliance with child find regulations, and some of their determinations might create some problems for the kind of process we just heard about, so I think that's another group besides the American Academy of Pediatrics, for instance, that should really been involved on a national level in discussing this.

KARL WHITE: I think you're absolutely right, Beppie, so Would you take care of that by our next conference call?

LESLIE POOL: This is Leslie Pool in Georgia. We've been struggling with some of these issues about Part C eligibility also with our program, and I think one of the things that would be interesting from the data that you all are collecting, Karl, would be for -- our program has a real interest to see whether or not those states who actually include children with more mild to moderate hearing loss in their Part C eligibility are finding that they're serving a larger percentage of children than those who limit their eligibility for severe profound hearing loss. Because one of the concerns that our state program has is that if they change that eligibility to include those more moderate hearing losses, it's going to overwhelm their system.

KARL WHITE: Yes, it probably won't "overwhelm the system" but it will add a significant number. This is why I say that. About a third of all children with congenital hearing loss have severe/profound bilateral hearing loss and are probably being served right now. If none of the

children with mild and moderate and unilateral losses were being served, it would represent about an 11 to 12% increase in the total population of children being served, to begin serving them. That is a significant increase, which would take significant resources, but it is not catastrophic. I think your point is very well taken.

ARLENE BROWN: Karl, this is Arlene from Colorado, and I can't resist the opportunity to mention something about unilateral hearing loss. We did a pilot project on 30 children, and I was actually surprised to find that 30% of those children had a delay in communication and language skills in the birth to three age range, so while many states have been waiting to decide how to address unilateral hearing loss, we've -- with this -- the outcome of this pilot project, are feeling that we better start looking at that seriously.

KARL WHITE: I'm glad you brought that up Arlene, because these children with unilateral loss are an incredibly important population who can be dramatically helped by early intervention programs. These children represent about a third of all the children who are being identified in newborn hearing screening programs and there's very good data showing that those kids will be substantially delayed if they don't get early intervention services. So keep mentioning this point.

JENNIE COOK: This is Jennie Cook from Maryland. Did you say 30% had delay in the unilateral population?
KARL WHITE: Yes, in the unilateral.

UNKNOWN SPEAKER: What was the hearing loss degree for those unilateral hearing loss in Colorado?

ARLENE BROWN: Let me think a second. I don't have it in front of me. I know the ear didn't matter. The delay didn't show until 18 months of age. That's not surprising. Karl, if I send it to you, will you post it?

KARL WHITE: Sure. There are also some slides on our website about the consequences of a unilateral loss that show that by the time children with unilateral loss reach the 2nd to 4th grade, the amount of delay, on average, compared to children with normal hearing was about a year-and-a-half to 2-and-a-half years of growth in terms of language, math, and/or social skills.

UNKNOWN SPEAKER: Karl, this is (inaudible) in Wisconsin. A quick question. I think it relates to your slide 10. And again, where you talked about states that had operational zed their eligibility definition. We in Wisconsin have chosen not to, and we're -- in our -- we have it as a diagnosed condition with high probability, and we say that unilateral, bilateral, those are significant losses, and not to put into administrative codes specifics so that we have the flexibility to not be locked into, for example, severe profound bilateral. Do you have a gut feeling about how that has played out in states, those that have operational zed it? Has it in fact been used as a gatekeeper to keep kids out versus getting them in, and what would be strategizing for states? What's the best way to approach this as a state, other than to be able to have the most lenient, if you will, eligibility?

KARL WHITE: Yes, this is an important issue, Sharon., and as long as you were the decision-maker, then I would feel great about having a child being served in a state like yours where there weren't clear guidelines. I guess what I worry about is if the decision-maker is someone who is trying to save money and there is not an operational definition. Then a parent who has a child identified with a moderate bilateral hearing loss may come to the program and have the

program say no, there's not a developmental delay yet and we only serve kids with profound losses.

UNKNOWN SPEAKER: Yes. And what's not included in that -- and I just looked at your link -- is that, for example, in our state, there is an accompanying document that's part of a work group that kind of lays out the (inaudible) evidence based science that relates to why these kids meet that criteria. But, again, each -- you know, what happens in a local community is hard to monitor on a regular basis to make sure it actually gets inputted in the way you hope.

KARL WHITE: Right ,we will include those documents in the information we are putting together.

UNKNOWN SPEAKER: Yes. And I'll follow up with them as well

KARL WHITE: Good. But I think that's an incredibly important point. From a legal perspective, when we think about protecting the rights of parents -- and I don't want to get too legalistic about this, it makes sense to make sure parents know exactly what services they have been promised. You don't want parents to be in the position of having to persuade someone to give

Debbie: Karl, this is Debbie from Michigan again. And earlier we had talked about educating different groups, and last year at the national conference, we heard from Dr. Judy Niemeyer, an investigator at the University of North Carolina, and she had set up early intervention national training resource and is that still available?

KARL WHITE: Yes, the CENTe-R project is still very active. They have developed a lot of new material and you can check it out by visiting their web site at http://center.uncg.edu. Judy Nielsen will be representing the CENTe-R project at the Annual meeting again this year.

JENNIE COOK: This is Jennie from Maryland. With all the state budget cuts, are -- all of our laws are being looked at with a fine-toothed comb. We're going to have to justify why this is a law in Maryland and why they should keep it. And why we should -- they should provide money to it. And we're going to have -- be having to pull some outcome results from our universal newborn hearing screening, but we keep on hitting a brick wall when we try to get share information -- or get information from our state education coordinator for Part C to try to share information. We keep getting hit with FERPA, you know, the privacy act, we can't share any of that information. Are other people having that problem?

UNKNOWN SPEAKER: In Michigan, we are.

KARL WHITE: No, we haven't had that problem here in Utah. Part of that is because both our Part C lead agency and the EHDI program are within the Department of Health. But even when that is not the case, there is certainly a mechanism within FERPA for memoranda of agreement between agencies for sharing appropriate information. So I think it's an issue of helping the relevant people understand why it's important and then working out appropriate interagency agreements for that to happen. As I understand it, FERPA in and of itself does not prevent that from happening.

UNKNOWN SPEAKER: But there can be memorandums of agreement?

BEPPIE SHAPIRO: This is Beppie. One of the easiest ways to do it, if you don't need to track individual children, is to ask your education agency for summarized data for children with various categories of hearing loss. Now, speaking in Hawaii, our education system finds it extremely difficult to do this. But it is, nonetheless, something they can legally do. And there might be some way to help them analyze their data system to give you that information.

UNKNOWN SPEAKER: Okay. Thank you. And another question. Back to slide number 18, you said 84% of Part C programs pay -- would pay for the diagnostic evaluation?

KARL WHITE: That is correct, if the child is not eligible for Medicaid and if the family had no health insurance.

UNKNOWN SPEAKER: Oh, I see. Like a payer of last resort

KARL WHITE: Yes, Part C, by law, is the payer of last resort.

UNKNOWN SPEAKER: Okay. That's what ours is. I was --

KARL WHITE: Right.

UNKNOWN SPEAKER: There's very few that go to them for that. Okay.

KARL WHITE: Yes. I mean, Part C, by law, is the payer of last resort. And those numbers are preliminary too. Those will change as we get more data in.

BEPPIE SHAPIRO: Okay. And Karl, this is Beppie, and what puzzles me about that statistic is, I don't know how many states are Part C entities, are regarding children as Part C children from the date of screening, so if they weren't regarded as Part C children until after an evaluation, then it seems -- I guess that would be an evaluation for eligibility, so I guess they would pay for them as that.

KARL WHITE: Right. But in my opinion the Part C law is very clear in pointing out that a state really doesn't have the option of not regarding them as a Part C child until after they've been diagnosed with a hearing loss. I know some states have taken that position, but I think it's contrary to the law. The law says very clearly that if a child is suspected of having a disability and is referred to Part C, they have to take care of that child.

Krista Biernath: Are there any other questions or comments? This has been a nice discussion. Thank you, Karl, very much, for your presentation.

One last announcement, I know there's not as many people on here -- a lot of people are hanging up -- but if anyone has any comments or suggestions for topics for the teleconference or for improving the teleconference, if you could just send me an e-mail, I would really appreciate it. I'm looking for any ways that we can make this a valuable experience for the participants.

I'm going to give you my e-mail address. It's KBiernath@cdc.gov. If you could just send me your comments, they'll be greatly appreciated. Our next teleconference is the first Tuesday in March. Does anybody have any other announcements? Okay. Then I just want to thank you

for joining today, and especially a special thank you to our two speakers and we'll see you in March. Thanks, Krista.

(Call ended at 3:00 p.m. EST)