Please standby for real time captioned text.

In just a few minutes we will start the Infant Diagnostic Hearing Evaluation Survey Results survey preliminary results. We are having some technical barriers right now, but the program should start in a few minutes. Thank you.

On behalf of the Early Hearing Detection and Intervention program the center for Disease Control in Atlanta will come to the teleconference on Infant Diagnostic Hearing Evaluation Survey Results Survey results. The CDC EHDI team lead is on a site visit. Our presenter today is Karen Munoz at Utah State University.

Before we begin the formal program, let's go over a few logistical items.

As in previous programs, today's session is using technology that has initially muted all phones except those of the presenters. This will reduce interference on the lines for clearest reception.

Also to keep the audio lines free of interference, we will be handling questions electronically today. Please look at the toolbar at the top of your screen. Click on the item "Q&A." You will see a notepad area that you can use to type in your question. After you've typed in your question, press "Ask" to send it to the presenter. We will monitor the questions and Dr. Munoz will answer as many as possible at the end of the session.

If you do not have the link to the visual portion, please e-mail me this address srichardson4@cdc. gov. Again, that is srichardson4@cdc.gov. The session will be recorded both visual and audio and available later. Today, because of some technical situations, Dr. Munoz will be presenting the lecture and I will be

advancing the slides and also reading the questions at the end and, of course, Dr. Munoz will be leading the session for the entire session.

Dr. Karen Muñoz is an assistant professor of audiology at Utah State University in the Department of Communicative Disorders. Her focus is pediatric audiology and she has been actively involved in efforts to support the early identification and management of hearing loss in children. In addition to her faculty appointment, she also serves as a deputy director of the National Center for Hearing Assessment and Management (NCHAM) at Utah State University.

We will now turn the program over to her. Please go ahead, Dr. Munoz.

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Thank you for the opportunity to be here today and share some results we are getting on the the diagnostic during surveys. This is a preliminary presentation. We are still getting surveys in and still doing analysis, but we have gotten quite a bit of information that is interesting and will be learning more as we finish going through analysis.

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I'd like to acknowledge some people who have been with us. Irene Forsman has been a real advocate for finding out and exploring what we can do to get timely services for infants in a appropriate manner so we take full advantage.

Lauri Nelson is a assistant professor in Deaf Education and is helping with this because

Pat Rousch, an audiologist, helped with the survey design and other portions of development and Natalie Goldgewicht and Timothy Lake are two students that are working really hard that putting data set in and pulling all of this together, as well. I want to make sure that everyone is aware of the team that has been working on this.

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If you are on this call, we know you are interested in EHDI, Early Hearing Detection and Intervention programs, and it is probably not news to anyone that the objective of having an EHDI program is to provide an opportunity for the early identification of hearing loss in babies who are born with hearing loss and this is probably a recap. With what screening done by one month, diagnostic testing completed before three months, the hearing aid fitting before that-these are the goals that have been talked about as the 1-3-6 goals and they are looking on the outside. The earlier we get these taken care of, the better for the baby and, really, the intervention cannot begin until a diagnosis has been confirmed with the appropriate detail to guide the intervention decisions.

We are looking at once babies they'll newborn hearing screening and needing to go to a diagnostic hearing test, what happens and that is what the focus of this is.

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So, the purpose of the survey was to ask three basic questions because we wanted to learn what are the practice patterns for thin diagnostic testing in the U.S.? How well are the audiologists meeting the diagnostic testing needs of babies that fail the screening and what are the challenges that exist to providing timely diagnostic testing? There is not lot of anecdotal data and people talking about challenges around this topic. It is are to get them in on Time for a variety of reasons but not any real data to draw on it. This survey was trying to get some more solid information so we can learn about these issues and find better ways of improving the care for babies.

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So, the participants for the survey, basically, all of the state EHDI coordinators were invited to take part in this and asked if they would like to mail surveys to all of the infant diagnostic centers in their state and through that, 30 states chose to participate. The paper survey was mailed out to the state EHDI coordinators and they mailed it to the individual centers and did that beginning in August and we are still collecting surveys through this month. There were two reminder postcards mailed out to read each center to help get surveys in with an option to

go online and fill it out if they no longer have the paper surveys. The instructions were that one survey should be completed per diagnostic center and the thought is that even if there is more than one audiologist there, the practice patterns should be similar across people within a particular setting. One thousand thirty-five (1,035) survey copies were mailed and some could not be delivered and we had 336 completed surveys back. I know it has gone above that at this point, but that is what I had at the time I looked that this last week and the return rate was 33% at that time.

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So, the map you see in front of you with purple dots represents the number of different geographical regions that we have data from. Eight gives you a visual sense of where we are learning information from.

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I will not go through this table, but if anyone is interested in looking at that, you can see how many surveys were mailed by state, and how many were returned (in parentheses) and how many completed surveys we have gotten back from that state and the return rates by state. It is broken down for you there.

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One of the things that we wanted to find out was what types of centers are doing the infant diagnostic testing. Forty percent (40%) are hospitals and 22% are medical clinics. Private practices make up another 22% and 16% identified themselves as a different kind of setting. On this slide you can see what those other settings were. University clinics and the number in parentheses is how many people send out, nonprofit clinics, ENT, public school settings, outpatient center. These are the types of places that are participating in infant diagnostic testing. Now, they're back our a number of pieces of information we want to know about this process. I will be going through different aspects of this.

That one of them is the diagnostic test Battery. Would have baby is referred to the audiologist, there are a series of tests that need to be done and they are what

are going to provide that diagnostic detail to understand the nature of the hearing loss that exists and that information is what will be used to plan treatment and intervention. The Joint Committee on Infant Hearing, or JCIH, has our recommendations and guidelines that they put out in 2007 and within those guidelines, this is the battery that they recommended, that they suggest, basically, and it includes high frequency tympanometry, and the ability to identify [ indiscernible ] ABR with a low and high frequency, bone conduction ABR and Beaver observation audiometry. They will add another component to what we understand about the hearing loss. This would be the recommended battery for a comprehensive test.

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So, you can see that for 284 of the facilities, we were able to look at a little bit of detail into that battery. There is more analysis to be done on this. These numbers might change somewhat, but this is the initial piece that we have. Of all of those 284, five percent (5%) of those diagnostic centers said they were performing all of the tests in the JCIH battery. Five percent (5%) were doing more than that, more extensive. Forty-seven percent (47%) were missing some components of that diagnostic battery and there is some risk of misdiagnoses when that happens depending on what component is missing. This is where I will have more detail after we finish analysis and the presentation will be at the EHDI conference in March. There is some risk in misdiagnoses depending on what is missing. We have some diagnostic centers using different combinations of tests. There are 39% that were doing a partial battery and enough tests missing from the battery that there would be insufficient detail to initiate intervention. They are considering a diagnostic test but not enough detail to take the next step. What that means is there is a high risk for delay in moving forward with treatment with limited information and 4% said they did not do diagnostic testing.

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So, another question that comes up about the locations that do diagnostic testing is under what conditions they do that test battery. So, one way to do that with a

little baby is with natural sleep and they come in hungry and tired and you test them while they are taking a nap, basically. Another way to do is to sedate them with a mild sedative so you know they are going to sleep and some locations will do it in the operating room so they know they will be asleep. You can see that 80% are doing it during natural sleep and 31% is sedation and 33% in the operating room. There are some pros and cons to these approaches that I am not going into in this discussion and was not part of the survey, but I guess we will get some indications of that with the other pieces of information that we will share.

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One of the aspects of testing is we want it to be timely. If you recall the JCIH guidelines said it should be done before three months of age. So, we asked centers what the average age was when they do it diagnostic testing for each of those types of conditions. Natural sleep, the average age was two and a half months. On average, testing is getting done prior to reaching three months of age. For sedation and operating room, rather than asking the average age, we ask "What is the minimum age at which you will do diagnostic testing under sedation or in the operating room?" This is the average minimum age across facilities. You can see it is a little over four months for sedation and almost five months for the operating room. That means, on average the minimum age which it will be considered is later than the JCIH guidelines. The babies have to wait until they are old enough to have those kinds of things for exudation and operating room in Order for testing to be completed.

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I thought it would also be interesting to take a quick look that the range of ages across facilities. If we look at the age of testing the range of for natural sleep, it is anywhere from one month to 6 months. Sedation, one month to twelve months and in the operating room, one month to 10 months. Based on where someone is, there is quite a bit of difference in the age at which testing is being completed.

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Another question that facilities were asked is, what challenges they experienced at their location in completing testing prior to the three months of age. Interestingly, 65% of the people responded said there were problems with the parents' complying and scheduling the appointment. Notlot of what we are learning will the to more questions and one that jumps to my mind with that is, what kind of information is being given to parents to help connect them to the next step? What little barriers are they having in getting connected so that they can schedule? That is a very high percent. Presence of middle ear fluid, 56%, is another interesting question. Are audiologists typically waiting until the fluid goes away to do the diagnostic test, or are they completing the diagnostic test and identify and that this looks like it is a mild conductive hearing loss because of fluid or potentially a mix of hearing loss that has meant permanent sensorineural component that we need to treat in a more aggressive manner? If the infant has other medical health issues, 42%, these might be babies in the NICU. Thirty-two percent (32%) are testing that needs to be redone. That is an awfully high percent for getting appropriate testing done. There are things getting in the way of the testing process. Parents live far from the facility, 31%. That leads to access issues. Parents have transportation problems, 30%. Appointments are booked out several weeks, 29%. That, again, might have access to enough people that are doing the appropriate testing. Lack of timely referrals from the screening speaks to a connection between the hospital and diagnostic center and getting the transition done smoothly. There are some other reasons brought up and only 2% brought up that they only offer testing under sedation. For that reason, it is delayed. That was a rather small percent.

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[May I step in for a moment?

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Yes.

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If people have questioned and cannot send them through the Q&A function, please feel free to send them to the e-mail address, srichardson4@cdc.gov. I will be sure to be monitoring that and bring those up so that your question will get answered during the session. That is srichardson4@cdc.gov for question. Thanks. I will go to the next right. Go ahead, Karen. ]

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There were other reasons that were brought up for challenges in getting the testing completed before three months of age: one the new reimbursement or insurance coverage issues. Insufficient staff was brought up, the infant coming in not properly prepared for testing, lack of equipment, which might be some of the places that only did partial testing, no shows for appointments or parents' and physicians' lack of understanding of importance.

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Another aspect of this that was important to look at was, how long do people need to wait for an appointment when they find out their child fails the screening and they need a diagnostic test, and did that differ depending on the condition of testing being natural sleep, sedation or the operating room? This slide represents the average in weeks that people needed to wait to get in across facilities with the average. For natural sleep, on average, they were waiting three weeks. For sedation, on average, five weeks and in the operating room on average, four weeks. Let's go to the next slide.

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Looking at a range across the facilities of for natural sleep it was as little as three days to get in some facilities and up to three months with others, quite a difference there. Sedation was four days 33 month and the operating room, two days up to five months because the wait time is different from one location to the other and some people are waiting quite a bit of time.

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A little bit of additional detail for the different conditions. Natural sleep ABR, remember on the challenges it said that 32% had trouble getting the testing done because the baby was noisy-there were noisy results and they needed to repeat it. That has been brought up by a number of people with natural sleep ABR that it is hard to get clean results and we wanted to find out how prevalent that was. Of the facilities that were asked during the past six months, approximately what percent of the ABR tests could not be interpreted due to excess of muscle movement lies? On average, 18% said they could not be interpreted and that ranged from 2% all the way to 100%. Some facilities almost never have that problem while other facilities are reporting they always have that problem. I think that is a real interesting spread and the related question was, approximately what percentage of the ABR tests need to be repeated to verify the results? How often do they think they need to do it again to know what they got? The average was 23% and ranging from 2% to 100%. One of the ways we will be digging into this a little more is for the facilities reporting 100%, we want to look back and see how often testing is happening there and try to connect some of the other questions we asked and understand why it would be such a high percent?

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A little more detail on natural sleep: we ask what the average time that was scheduled and on average to it two hours, with a range from one hour to 6 hours. It would be interesting to see the facilities having trouble with noise or other issues, how long the appointment is? Are there any connections? We are going to look into that a little more. We also asked the instructions they thought were helpful to successfully complete their battery, what they are telling parents ahead of time to lead to the a successful test. Ninety percent (90%) said to bring the infant in sleep-deprived and 94% bring the infant in hungry and ready to eat and 82% bring items to comfort them such as a pacifiers, bottle or blanket. Twenty-ne percent (21%) said not to put lotion on the infant's face and 23% have some other instructions. For example, do not bring the siblings and do not let them sleep during the car ride. Educate the parents about the appointment, such as how long it will take and the importance of scheduling the appointment during

the normal nap time and if the baby is asleep in the car seat, bring them in the car seat. Prepare the baby ahead of time, such as diaper changes and arrive early to feed the baby and bring someone to help keep the baby awake in the car. These are things that facilities have reported to have a successful test.

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Also, looking at ABR with sedation trying to find out what is happening with that, 75% of the facilities that did that says they use chloral hydrate. Others use other types of medication, and I have them listed there below. Part of the procedures for a baby is to have now Mainers available to monitor the vital signs during the test procedure. One of the questions we have is for the sites that do sedation whether they have a nurse available to monitor the baby throughout that procedure and 88% said they do have a nurse available which means that some of them do not have a nurse available. That is interesting.

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One thing that we wanted to find out is when a baby is getting an ABR under sedation if there are instances where it is difficult to get all of the diagnostic information needed, because one of the arguments for sedation has been that you can get them sedated and make sure you get all of the information you need at the time. About 9% said they had trouble getting all of the testing results they need. Percentage ranged from 0 to 100%. There are some immense differences with that that we will look into a little more in detail. Because these were preliminary results, I wanted to make sure to leave a good chunk of time for questions. I would like to move into that next.

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This slide is inviting questions and, so far, we have two questions. We will take the in Order. Maybe points of explanation of some of the slides. One clustered: When most of those tested in the operating room also be sedated prior to [ indiscernible ] placement?

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That is a great question and one of the pieces of information we have not analyzed yet. We ask in the survey, some of the different reasons why they might be doing testing the in the OR. Are they doing along with other procedures? We will have that data but do not have is yet.

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Okay. Another question: On the challenges slide, how are these determined by the facilities completing the survey? Are these the obstacle as identified by the parents or reflective of what the center thinks is happening? Let me see if I can go back to the slide.

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That is a good question. This is from the perspective of the centers and they have lists of potential challenges and were invited to check off as many that applied. Most people have more than one challenge identified that they feel like they are dealing with within their center. This is from the center or facility perspective on what they think is part of the problem. An interesting thing that I would like to mention is we are doing another survey that looks that the same issue of timely and the diagnostic testing, but we are going to be sending it to parents to get it from the parent perspective and that will be going out through Hands & Voices in December. They are getting at the same pieces of information although not order the same, to find out from that side and perspective what happened with the parents in their individual experiences with infant diagnostic testing so we can learn more.

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Okay, that takes care of the questions submitted so far as. If people have questions that have come up after hearing the slide or in response to the answers you just heard, please feel free to send them in and we have another one coming in. Of 47% of diagnostic evaluations I see some components-which components were most often missing? Also, which components result in not enough detail to initiate interventions?

Okay, so, let's say that is two questions because the first one is the one with the diagnostic battery missing components. There could be some risk. One of the most common pieces missing from that is not doing behavioral observations audiometry. That might not be meaningful for anyone who is not an audiologist on the call. That might not cause any major problems because that test is not the main test that will identify the part of the ear that is the problem or the level of the hearing loss. What I will be breaking out is how many of that 47% fall into that category versus how many are leaving out things like the OAE. People will do a click stimulus with the ABR that is looking that some neural function but will not look that the cochlear microfauna. That is not piece of information that helps with the diagnosis. There are some finer details of being left out. Bone conduction is another test left out, frequently. I will be going through all of that and some will be more significant than others. Let me know if I did not answer that in enough detail for everyone.

The second part of that question is what would be a partial battery that would leave insufficient detail for intervention? That would be a battery that includes only OAEs or tympanometries because they only do a partial test and you have to send them somewhere else and that results in a delays because they might do tympanometry and OAE the only click on ABR but if you have not be hearing loss and have a ABR with a click. Again, I apologize for how technical this is and myself but that does not give you frequency specific to fit a hearing aid and take the next step. We need to get frequency-specific threshold for each ear in order to appropriately move forward speed of the partial test batteries were having no frequency specificity and might only have something like OAEs and tympanometries and would not be complete and comprehensive enough to the extent to know the type or degree of the hearing loss or configuration across frequencies at all. Also, let me know if you need more information about that, too.

We have two questions that might be related to one another. Will states receive the results from the facilities in their state? Will it include identifying information? It seems like there is opportunity to provide education and technical assistance to the specific providers.

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That is a great question because the state kept participating will get an individual report on the results for their state, as well as the National results so they can see how they compare to that. It is not identifiable. We made the decision that this is an anonymous survey because we wanted people to answer not with what they ought to be doing but with what they are doing. Which facility gave us which facility, we only know what state it came from. There could be educational opportunities based on the results of it that could be put out for audiologists within different states.

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There is a related question. When can we expect state-specific and formation with thanks at B in.

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My goal is in January. There is not lot of detail packed into this survey. My goal is to have-and finish analyzing- it by the end of January. I will make sure that the states that participated will have their state-specific information before the EHDI conference.

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Okay. Another question: Do you have an idea of how many of those complete batteries are due to [ indiscernible ] ABR and not being done?

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I am not sure if the person that asked this, when you say incomplete battery if you are referring to [ indiscernible ] missing components or partial batteries? I think you mean diagnostic battery with missing components and, yes, a number

of those are due to bone connection. What I will be doing is pulling out in a way that is easy for people to understand what the components are that are typically missed and how frequently are they being the best. It is a rather complex data set and wanted to have that for you today, but was not little bit too complex.

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Another question: Where does ASSR fit into diagnostics? I have seen center is using ASSR and Notes ABR, click or [ indiscernible ].

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That is another piece of the test Battery question that I am pulling out. I am looking at how often centers are doing ASSR instead of the ABR or instead of the tone [ indiscernible ]. I have had people say that they do click ABR and ASSR which is auditory steady state response testing, which is another technology to get frequency-specific information. Some facilities are doing click ABR and ASSR and some are only doing ASSR. I am pulling out how often that is happening, as well as. We have places looking at that frequency-specific information but doing it in a different way which does deviate from some recommendations that JCIH has out there right now.

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Okay, another question. Are you able to follow up with some of the facilities, specifically, and do you wonder what those sites that were reporting 100% of the time they were not able to get the results, perhaps they answered the question improperly?

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Unfortunately, I will not be able to check with the facilities because it is anonymous. I did not know where they come from, I only know the state. For those that jump out as being unusual, I will cross-check it with how often are they doing testing, what type of a facility it is and look into it deeper and see if there is any other connection that I could make that might shed some light on and see how many places said that, as well.

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Okay. There are no other formal question submitted right now. If the answer to one of your questions did not get exactly to the point that you had hoped, please send those in now through the Q&A feature on the top of your toolbar on the screen or by sending an e-mail. We will give a few more minutes for some final questions or comments. Karen, do you have any comments or questions you would like to put out to the audience?

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No, I guess not. I was going to try to look-I have some of the details that I have been asked about, the percentages of the testing on what was missing, I was going to take a quick look at that and see if I can share more.

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I know we have one more question, too. Are your slides available to share with our hospitals?

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Well, I do not know, are they available, Steve?

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As far as physically sending copies of these slides to people, we can do that from this office here. The main thing is the person controlling the data and knowing where it is in the final form and how you feel about the release or use of preliminary results.

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I do not have a problem with that as long as you recognize that this is not done and so it is preliminary. This is just an idea of what is happening but there are more surveys coming in and we have more analysis to do is because this would be something you want to look at as a trend emerging at this point until we have the final analysis done.

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If that is fine with you, Karen, if people want a copy of the slides, before they can get up on the website or more generally available, I would be happy to take individual requests and the same e-mail, srichardson4@cdc.gov. I will send out copies of the slides that were in today's presentation.

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That sounds fine.

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Any other questions or comments? The Q&A feature or through e-mail. All right. If people do think of questions in the meantime you can send it to that same e-mail and we will forward them to our presenter today. If there are no further questions, we can formally close the session.

We welcome your ideas, too, on how to improve these teleconference sessions and let us know what you liked about today's presentation and what we can change to make the future teleconferences more useful. Send your questions to gol8@cdc.gov. Thanks, Dr. Munoz and thanks to all of you for taking part in today's teleconference. Goodbye.

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[Event concluded ]