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Evaluating Jurisdictional Early Hearing Detection and Intervention Information systems

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>>MARIA SANCHEZ: Good afternoon, everyone, I'm Maria Sanchez, an evaluator on the CDC EDHI team. Krishnaveni Subbiah will be presenting on this team well this is for the opinions expressed in this presentation are those of the presenter and do not necessarily represent the official position of the center for the disease control and prevention.

Here we have the learning objectives for this be presentation. During this presentation you will learn the overarching EDHI logic model that establishes attributes and you will receiving a summary of the findings from previous submissions of evaluation plans. So let's get started. Why evaluate jurisdictional early hearing detections and information system. First because evaluation is essential to public health in order to improve program and provide accountability to policy makers and stakeholders.

Including evaluation into their regular activities for the EDHI IS state jurisdictions to figure out what is working well and how the system can be further improved. Also to share best practices among jurisdiction and stakeholders. The evaluation component was incorporated for the first time into the regular activities for the CDC EDHI program in 2013. At that time CDC required 52 awardees to develop and implement an evaluation plan to assess the EDHI information system. So 2014 to 2015 CDC worked together designing and implementing the plan with jurisdiction and in July 2016 jurisdiction shared findings with the stakeholders and CDC. As a program we learned a lot and now we would like to share with you some of the results and some of the lessons learned that we have.

First, I willingly quickly over the evaluation design. Developing a standard evaluation for a large group of jurisdiction is an extensive job that require a lot of review and advance preparation. So the first step was engaging stakeholders. Jurisdiction was started by selecting the evaluation team and engaging the stakeholders in the evaluation. The second step was to describe the problem and target a specific area that jurisdiction wanted to evaluate. Because evaluation can take hundreds of different ways, it's important to get consent from your program staff about what is more important to evaluate, what is more real sticks, what is more physical in order to maximize the effectiveness of an evaluation so after meetings and discussions and conversation with CDC EDHI members and the team is it was decided that the focus of this evaluation was the quality of the data, the EDHI IS and the EDHI program as a whole. So we started by examining what the EDHI information entails, how the system is supposed to work, the goals, objective and criteria for success. As part of this process we created a logic model to describe the relationship between the program activities and the intended outcomes. Here we found the final version of the EDHI information system logic model. We identified in red some of the quality limits that we wanted to evaluate, like the accessibility of the EDHI system among hospital staff, the quality of the data, the completeness of the data, the flexibility of the system. So we linked the logic model with some guidance for evaluating public health surveillance system. These guidelines were published in the CDC morbidity and mortality weekly report in 2001. This report was developed to promote the best use of public health resources by developing efficient and effective public health surveillance system. It was positive to have this guideline as a framework for reference. This graphic shows the attributes you must consider when developing evaluation for any type of surveillance system. We also include the data quality assessment, completeness, uniqueness, timeliness, accuracy, validity and consistency. Now I will turn to Kris and she will explain in more detail the attributes.

>>KRISHNAVENI SUBBIAH: As Maria was saying because had you been health systems vary in method, scope and purpose, attributes that are important to one system may not necessarily be relevant to another. A public health surveillance system should emphasize those attributes that are most important to the objectives of that system. For the FOA2013 to 2016 evaluation these attributes were the most relevant to evaluate EDHI IS. We will move on to the summary of the findings of the previous cycle of evaluation plans. This figure shows the number of EDHI IS attributes see evaluated per jurisdiction. There is a range from 1 to 6 attributes with 27% of these plans evaluating two attributes. This next figure shows the number of jurisdictions who evaluated each attribute type. You can see more jurisdictions evaluated acceptability, accuracy, completeness and timeliness and I will focus on these four attributes in the following slides and mention the common evaluation comments that we saw across those plans. The first attribute is the acceptability, which is evaluated in terms of the willingness to participate and use the EDHI IS. One example of this would be to what extent do hospital staff in the state know about the jurisdictional EDHI program as well as use the EDHI data reporting module. We found that there was a high acceptability of the EDHI IS among hospital staff in most jurisdictions who reported on this attribute but we also found that several jurisdictions said that not all staff were adequately trained to report and that the staff had identity lack of knowledge as the primary reason why they were not reporting. Another common issue was the information with transfer babies. Infants born outside of the jurisdictional EDHI hospitals were not able to use the EDHI IS to report information in those particular jurisdictions.

The second attribute is accuracy. Which is defined as the extent that data are correct, reliable and certified free of errors. The most common issues reported in these evaluation plans were about discrepancies in the number of births between the EDHI IS and other systems, and other scenarios were that baby's names were not real or misspelled and mother's contact information, particularly phone number was missing or incorrect. Another recurring comment in these plans were data entry errors with screening results including whether infants received or did not receive services. The third attribute, completeness is evaluated as the proportion of stored data against the potential of 100% complete data. As you would expect no jurisdictions had commented on 100% completeness but the common limitations were unknown demographic data, no EI data due to FERPA issues and an important one was missing information from home births, transfers or NICU babies and reason for not receiving services and incomplete information on risk factors and other conditions.

The final attribute I will talk about is timeliness and this is evaluated in terms of reporting or collection of data. Most jurisdictions did not have issues with one month of age reporting however there was a variety in how live the screening results were, anywhere from less than seven days to three weeks. In addition there were also a few comments about concerns with audiologists reporting and also variance in hospital reporting, which ranged from an average of 45 days to 90 days. Thought this process there were a few successes and lessons learned. Afternoon finalizing the first cycle of evaluations for jurisdictional EDHI IS, the evaluation capacity was increased among program staff and jurisdictions. Relevant information was gathered which helped jurisdictions to identify action items and potential activities to improve the EDHI IS as well as the quality of the data. We learned that the acceptability of the jurisdictional EDHI IS and the timeliness of the documentation of hearing screen data was good among most jurisdictions. The completeness and accuracy of the data, however, still needed more work. Now I will hand it back to Maria who will go over lessons learned and changes that we've made regarding the new FOI.

>>MARIA SANCHEZ: We also want to share some of the lesson learned and challenge we have implementing this evaluation. The first one is related to the accuracy of the evaluation. Because some jurisdiction adopted their own definition of each attribute of the surveillance system this did not allow to make comparison with other jurisdiction. The second lesson learned or challenge we found is related to the information in scope and selection because not all information that you collect is equally important. It's important just to select those attribute which are more relevant or specific to your outcomes. So we found that sometimes jurisdiction were collecting too much information and at the end what we really want is to disseminate your findings with your stake holder to define action items but this didn't happen at the end. Soto solve this issue, now CDC EDHI is providing additional guidance in the new FOA and also selecting just one attribute per year to evaluate.

Another issue we identify was related to the timeliness and dissemination and because there was a delay releasing the final report some jurisdiction were having trouble disseminating the final evaluation report and because there were stuff turned over those responsible for creating final report were not involved with the evaluation from the beginning. Now, again, to solve this issue CDC provided additional guidance in the new FOA and is asking to submit or disseminate the evaluation report sooner. As soon as you have some findings or as soon as you have even preliminary findings and you think that you are selecting important information that should be shared with some stake holder this is the idea, as soon as you have that information. So as a summary, we would like to say the quality of the data contained in the EDHI information system might be impacted by numerous factors. It's our responsibility to ensure that each system document on time the most complete, accurate and valid information to ensure that the system reflect the hearing and screening status of each infant born in the jurisdiction. So evaluation is one tool that can help us to reach this goal. We finish here but if you have any questions about this presentation? Please. Okay, thanks so much.   
(Applause.)

(Presentation ends.)

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