

MCHB/DCAFH

Let's Make Easy -

While Getting the Most from Your Hard Work on Child Death Review Reporting

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STEPHANIE BRYN: Welcome to the web cast. And thank you for joining. This web cast is entitled let's make it easy while getting the most from your child death review reporting. I'm Stephanie Bryn. We're very proud of the efforts and accomplishments of the national center for child death review policy and program, directed by Harry Cozelton.

Our speakers are from the national center and thank you so much for being here with us today.

Now, here are the instructions from the center for advancement of distance education, CADE, who make this broadcast possible and thanks again for the personnel for their assistance.

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We encourage you to ask questions of the speakers at any time during the presentation. You will simply type your question in the white message window on the right of the interface and select question for speaker from the drop down menu and then hit send. Please include your state or your organization in your message so that we know where you're participating from. The questions will be relayed on to the speakers periodically

throughout the broadcast. If we don't have the opportunity to respond to all of your questions during this broadcast, we will email you afterwards. And again, we encourage you to submit questions at any time during the broadcast.

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TERI COVINGTON: Thank you. Hello, everyone. And it's nice to be here. We're in Washington, D.C., just so you get a sense where we're at and I'm looking forward to this because I know many of you have gotten help death support from Heather and Esther so this is an opportunity for them to talk to you about some issues we're seeing in the reporting system as people have begun using it. We're hoping this will improve data quality.

Go to the next slide, please. We want to thank the states of Arizona, Hawaii and Michigan. They have already been doing in their own state some of the data quality work we borrowed heavily from and that we've learned from ourselves at the national center as states have gone through and started using the systems. We want to give kudos to those three states and all of you who completed the online survey we did to try to get to the issues and problems you're having with the system and then we want to thank Mary

Overpeck. She had formerly worked here in Washington, D.C. and she helped us a lot as we think through the reporting tool and the data quality issues with our tool.

Next slide. An overview of what we're going to cover today. We want to talk about why the report tool is important to you as a local or state child death review user, we want to talk about why data quality is so important and then we're going to spend some time reviewing selected problems that people tend to have over and over again and where we're seeing some discrepancies in how people are filling out the report tool and that includes a lot of issues related to section I. Everyone's favorite section they love to hate. The section on services and the section on prevention and then we'll talk a little bit about how you can use the standardized reports to start of maximize the work that you're putting into this system. Just so you get a sense of where we're at with child death review reporting, we started this just about 2 1/2 years ago and as you can see, the states in red are the states that are currently entering data into the system. We've grown really, really fast. That's exciting because it means that throughout the country now we're creating and selecting standardized reports on our children's deaths. And we're going to be able to at some point start using that at a national level, state level and local level to start generating more improved recommendations and really start making differences in terms of programming and policies to prevent child deaths so we're pretty excited about it. We have, I believe, approximately 45,000 cases already in the system. But this is really the first official training we've done on data quality so I think the time has come for this. We talk a little bit about why the report tool is important to you as the user. First of all, when you use the report tool and you use it effectively and you have completed all the way through to the end every the form as we'll talk about today, it can really help you meet your goals of improved services and prevention of child deaths. We selected the elements in this tool using a very participatory process. The tool wasn't developed in Washington, wasn't developed by a

few people. It was developed by, I think, 19 states and over about 36 people from around the country who spent almost two years identifying what data elements people felt were really important to have in this tool that would really push the issue of prevention. So even though there may be data elements that you think are, gee, I don't know why they're asking this, why they're asking that, it was really designed to try to really build our knowledge at a local, state and national level to understand the risk factors involved in the deaths. And obviously data is a huge part of the child death review process. This is hard for us to see. I don't know if you can see this on your computer monitors but when you do a child death review, most of you have a meeting where you share your information on the review. And what normally happens is some of that filling out the form at the review meeting, partially do it ahead of time or after the meeting is over, they fill out the form, put all of the information in the computer. All of you on the web cast are probably registered users. The information gets sent to servers online at the Michigan public health institute where your data is stored and then you're able to retrieve it based on permission levels so if you're a local team you're able to retrieve your local data. If you're a state program, you're able to retrieve data from all of the teams in the state and we at the national center are able to retrieve identified aggregated data across all of states and what the whole purpose is by retrieving the data, you should be using it to try to drive prevention efforts in your community. We conducted -- I'm sorry. An example of how states are using their data. Ohio is one of our favorite users because you have teams in every county and you have the state law that requires you to submit this data, I think by April of every year. 51 of the 88 counties that fill out this form in Ohio reported that they actually produce local prevention initiatives as a result of their child death review cases. That's impressive and it really shows when you're smart and you use your reviews and you use your data, you can really do things to prevent deaths of kids. I mean, you guys in the local communities to me are heroes because you're out there doing these hard reviews but using your reviews to

save lives. Ohio also said that the report that they reported an increase in cooperation and an understanding to identify gaps in services for children, improved barriers to service -- no. They reduced barriers to service by doing the reviews. They felt they maximized the use of existing services and increased collaboration among their partner agencies. That's an example of why it's important to use the data in the reports in a really smart way to make sure you're actually using the data. You folks are putting a lot of time to inputting the data. We want you to get smart and to start thinking about how to pull it back out and use it in your communities. But to do that, you also want to sure that you have good data quality. What we found is that there's some inconsistencies, even within states, sometimes even within the same teams about how they answer questions. But when you have good information on the circumstances of deaths and the involvement of the agencies, it can really guide prevention initiatives and it can provide consistent evidence for agencies and their governing boards so we want you to try to hit the mark in terms of how to answer the questions. We conducted an online survey to sort of give us a sense of what was happening in terms of data quality in the winter of 2008. 138 participants responded from 18 states. Right now I believe there's about 700 users across the country so it was an okay response. We would have liked to have heard from all of you and all of the users but we designed this web cast based partially on the answers to the questions and the issues and concerns that people raised when they answered the survey. We heard back from you about questions that you were asking a hard time with, questions that you weren't answering, questions that you were having a hard time getting information to answer and that's what we're basing this web cast on. I'm going to turn it over to Heather who is one of our senior data analysts and she's going to start talking about the primary data quality issues with the report tool and then we'll start walking you through specific data elements.

>> Thanks. Next we're going to jump into the heart of the web cast, focusing on data elements shown to be problematic, some individually. We're going to be going through the report tool, section by section so it might be helpful to have a copy of your report tool readily available.

Next slide, please. While you're taking a moment to find your paper report tool, we wanted to offer some suggestions about what to do if you find yourself in the dark about a particular report tool question. And our first suggestion might seem rather trivial and obvious but it's a reminder to please read the question and the response options carefully. If you have any difficulty understanding the intention of the question by reading the response, it might give you a better sense what we're looking for. Sometimes folks just aren't answering the questions that have been asked. Our second suggestion is to please consult your data dictionary. This is really a wonderful resource. One of the major findings that came out of the survey that we just talked about is that the majority of survey respondents indicated that they've only used the data dictionary between one and five times. And this is readily available as many of you know, when you're on the web based system, when you're doing data entry, it's available from a web link at both the top and the bottom of each screen. Additionally, if you go to the help page of the C.D.R. case reporting system, you can get a P.D.F. version of the data dictionary if you prefer to have that paper document by your side. But it really is a great resource. It's a great care and deliberation that went into the development of that resource for both the launch of the pilot version and version two of the C.D.R. case reporting system. The national center had a group of experts to aid in the development of this resource so please use your data dictionary. The third suggestion, if you're in the dark is to simply contact your state administrator and/or the national center. We're always there to help. We'll do our best to answer your questions in the timely manner. In general beginning to examine the data,

we're finding two problems, two general categories of problem with the data. Data omission and secondly, data inconsistency. And these problems seem to result from difficulties in understanding the individual question elements as well as I think the C.D.R. review meeting process itself. Are you getting the right people at the table, are you asking the relevant questions. Data is a critical part to the C.D.R. review process. So it's important to always think about how your review process is affecting data and ultimately the policy recommendations that you can make. So before we jump into individual questions, we wanted to go over three points that seem to affect data quality throughout the section of the report tool. The first is that we still continue to hear there's some confusion about when to use unknown and when to leave a question blank. Please check unknown if you tried to research the question but you just weren't able to obtain a response or -- and then please leave the question or not answer it if no attempt was made to answer the question or if the question is not applicable. Use the response category, other specify appropriately. Please make sure that the option you're putting in, other, specify, isn't already listed in the response options in the report tool. An example that I like to use to illustrate this is in section a, child information question a19, insurance data. We're finding that individuals are selecting other, specify and then typing uninsured when the response option none is already available. Secondly, we're also finding some responses in other, specify that are very close to already listed response items. For example, in section h we're finding that individuals who are typing -- are marking other, specify and writing in quilt when blanket is a response already listed. Please review those. If you do feel there's an identity category missing in the response options, please let us know. We're constantly building our wish list for version three. Third recommendation is the please be sure any definitions or rules by your state administrator or coordinator. If you feel that your team besides the interpreter, a particular data element in a specialized manner, it's important to get the approval of your state coordinator first. Thanks.

Next slide . Now we're ready to jump into individual question items from the report tool and the general format for the next few slides is that we're going to highlight the question number followed by a short descriptor of the question. Here I'm going to jump in here with section a, child information and the first point we want to make is in roared to a9 and a10 regarding residence. And this is an example of where we're both having a data omission problem and data inconsistency problem. You can see from the pie chart over 45% of the cases currently are not specifying residence type in the form. That's a huge data omission problem. This is an important question. We're hearing from some states that the particularly interested in foster care deaths so this is where you would go in the form to get that piece of information. So please try to complete that. Then a clarification on this is for newborns who have never left the hospital, residence is considered the primary caregiver. We're also hearing in section a where to mark tobacco abuse by question and you would go to a22. This is the substance abuse. Here is an appropriate use of the other, specify category. You're going to mark other, specify and type in tobacco in the text box. Next please. The next question we would like to address is history of child maltreatment and that question is found in sections A, B and C. They're listed on your slide. And what we're finding is that folks are not necessarily reporting unsubstantiated referral. Select yes next to the history unless the referral is completely falsified. The second point we would like to make in maltreatment is, again, we're finding this data is not being reported consistently so this is a reminder that your D.H. Representative should be bringing this information to your table.

This next slide shows a finding that was noted in the online survey in regards to Section B and C and again, it's an example of --

>> So if you're finding during your C.D.R. review you're consistently not answering questions, it's a good check on the C.D.R. process. You may need to review your process. Do you have multidisciplinary participation from the community? Is the review comprehensive? Is your review focusing on prevention and encouraging a dialogue and effective recommendations? If you're finding that you're not consistently answering yes to these questions, then the information collected in the system will be limited and ultimately will affect your prevention and recommendation. Even the gatekeeper questions in Sections B and C, for Section B that is caregiver types is only being answered 17% of the time right now and the gatekeeper question is Section C, supervision. Does the child have supervision is not being answered 19% of the time.

The next slide brings us to section b, caregiver income level and what we're hearing is that this question from you is often difficult for them to answer. Yes, we recognize that this question is ambiguous, is subjective and often the information is hard to obtain but it really is the best question that we could get, the best marker that we can use to get the answer so please do your best in your team deliberations to come up with a response to this question.

Next slide. We have a question, who is the caregiver versus the supervisor of a newborn who is premature and never leaves the hospital?

>> Say that again.

>> We have a question which is who is the caregiver or the supervisor of a newborn who is premature and never leaves the hospital?

>> Well, the caregiver would be the parents and the supervisor would most likely be the hospital staff. We're going to talk a little bit in a minute about supervision. Okay.

Next slide, please. Question C1, did the child have supervision. Our main point here in this slide is to remind teams to have a careful and thoughtful deliberation, meaningful discussion about supervision. It's not entirely just based on age and/or actively watching the child. An for example that we share here is an infant sleeping in a room next to their parents, even though the child was asleep at the time of the incident and the parents were in the next room, the child would still be considered supervised. And as I mentioned earlier but with the pie chart here indicates that in 19% of the cases folks are leaving this question not answered. So really important question. Please do your best to try to answer it.

Next slide, please. Next question is in regard to C4, primary person responsible for supervision. And a lot of questions we field here at national center in regards to this, I think it's due to the fact you can only select one supervisor in this section. And the data dictionary, your friend, the data dictionary offers some guidance about how to determine supervisor. So, for example, if there were two -- there are two supervisors at the time of the incident but one clearly had primary responsibility, please select that person as the primary responsibility to be the supervisor and if the supervision was divided equally, put the person in closest proximity to the child at the time of the incident. Have a meaningful discussion to come up with the response. If an infant never leaves the hospital, in most cases the supervisor should be -- or excuse me, the hospital staff should be considered the supervisor.

The next slide brings us to section d, incident information. And I think by and large the questions in section d are fairly straight forward and easy to answer but I think where people start to get tripped up is when the case is a natural case. Yes, the questions in section d seem to be more useful in regards to injury cases but at this time we're asking all individuals to go ahead and do your best to answer the questions on incident information for all cases so if you do have a natural death, consider the incident as the acute event leading to the death. If the child has a chronic illness, the incident dates may be the same as the date of death. And then a clarification on question D1, date of incident, newborn should not leave the hospital, go ahead and select the response option, same as date of death. The point is that another example of when I think some individuals aren't taking the time to make sure they're answering what the question is asking, these are clarifications in the incident section so for D2, time of day that the incident occurred, just a reminder that this is the time that the incident occurred. Not the time of death. So it could be the same. And then in regards to D4, place of incident, we want to remind folks this is a check that all apply questions. So if you have a case of a child accidentally run over in their grandparents' driveway, secretary relative's home and driveway in D4. And then a reminder that the question asks for the place of incident and not where the child was pronounced dead. And then for children who died of natural causes with no acute event leading to death, the incident place is usually the same as the place of death.

This next slide, we move to section e, investigation information. In this first bullet we're hearing that some teams aren't necessarily making the distinction between medical examiner and coroner and there is a difference so please make sure you're answering the correct one in e1. And then in regard to e4, scene investigation, you want to make sure that you're only marking those agencies that conducted a death scene investigation, not

necessarily the agencies that were present or for whom you got records for during your C.D.R. review process.

In this next slide, what we're hearing from users is that they're looking for guidance about how to answer question e8, investigation find evidence of prior abuse. If no investigation was conducted. At this time, there is no response option of not applicable so we are advising you just to go ahead, that if no investigation was conducted, please leave the question blank. Similarly what we're hearing in e10, death in licensed setting, action taken, sometimes this question seems a little bit ambiguous or not really appropriate if the death occurred in the hospital. If that's the case, go ahead and leave the question blank. But originally when we designed the question it was to get at death that occurred in a licensed setting. If you have a case where the infant died in the hospital, please leave that question blank. Now I'm going to turn it over to the other data analyst at the national center.

>> Can we have the next slide, please?

>> Now we're turning to section f to the manner and cause of death. Manner of death we would like to have chosen directly from the death certificate. The cause of death can sometimes -- there can be more than one cause of death on a death certificate. And we can't give a rule that applies to all cases like always use the first cause of death or the last cause of death. This is a team deliberation that you should decide on the cause of death that takes you to the richest data within section g. If a team doesn't agree with the manner and cause of death, there's room in section I that you should be able to record that and for cause of death, we usually give the example of motor vehicle that ends up in the -- like in the body of water and the child drowns and when we give that example, we want to use the motor vehicle because that leads us to the place in g where we can work on

prevention. We also see often on a death certificate SIDS with overlay. What we recommend to people is that they choose either a medical cause and SIDS or that they choose asphyxiation and suffocation. But what's important with SIDS with overlay is that the section f gets filled in. And the bottom line is what we would like to tell you is that we would like this to be a team deliberation but to select the cause of death that is on the death certificate. If the medical examiner has said both the manner and cause are undetermined, please check undetermined if injury or medical cause. They would like to be able to fill in sections g5 and our skip pattern only allows that to be answered to G12 right now. We're working with our I.T. people to be able to change that skip pattern. We don't know when that's going to come on board but it is something we're talking about since people said they would have that kind of information that they would like to record.

>> We have a question. Should we be inputting cases that were not natural deaths?

>> What was the question again?

>> Should we be putting data in the report on deaths that we're not reviewing but were natural deaths and we're aware of those deaths? We have that prerogative to do that, a team has that prerogative to do that.

>> That would be an individual decision. If they want to -- if that's what the team has decided they want to do, then yes. In section g1 we're going to move to the motor vehicle. We are considering a bicycle to be a vehicle and when you're answering the rest of the questions about the vehicle in that section, just consider that with the vehicle being the bicycle. If the child is a pedestrian, please mark none because child's vehicle is not relevant but we would still like to see the vehicle for the other driver. For question b, the

position of the child. If the child is rollerblading or skateboarding, we would consider that to be pedestrian. Same. We're still on motor vehicle. Section c and d, cause of incident and collision type. We get a lot of rollovers and for the rollovers, it's an option in C but it's not in D and so if they rolled -- if the vehicle rolled and hit SBU a ditch, we would like you to mark other event. For question g, the drivers involved, we know that a lot of times there's not a lot of information about the other drivers but during the review process, it may be that there is information there especially if we could get the driver's license status of all of the involved drivers but it may be for the age of the other driver that someone has a rough estimate. For example, oh, I think they were in their 50s, and for that it would be acceptable to put in a mid range put in 55 and if there is no estimate on the age, then you put in a 999 and the difference is that if you leave it blank, that would indicate to us that you didn't try and get the information as opposed to a 999 which should that you tried to get the information but it was unavailable. We did have a comment about making an estimate on the driver age and again, it would be a team deliberation. If someone was in their early 20s or maybe around 20 years old and felt it was -- they were not able to make a real good distinction but thought it was important to distinguish between an 18-year-old or a 22-year-old, then that would be a team decision to decide whether or not you want to use an able range or whether you wanted to put in 999 for unknown. In section g4, with a suicide by hanging, we have some teams selecting a cause of death of asphyxia and using strangulation in g4 and we have other people who are using cause of death as weapon with a rope in g6 and we would just like you to be consistent in your own state. Most are using asphyxia and strangulation. We have seen a couple with weapon and rope and as the national analysts, we might have to look in either space but for your local people, if they're doing data analysis, it would be -- it would be better to just put -- just be consistent. Moving on to section g6, weapon -- this is where physical abuse is going to be recorded if it's the cause of death. If it's not the cause of death, then put in the correct

cause of death and use section i to record the abuse in question 3. Section g9 which is poisoning, we've had some questions about what the difference is between accidental overdose and acute intoxication. This is straight from the data dictionary so you can go back and reference this. But the accidental overdose is unintentionally giving more medication at the higher dosage level than is recommended. Or it includes child -- the children ingesting agents without the knowledge that they were going to be adverse consequences. Acute intoxication is to recreational use or addiction. It excludes suicide which would be a deliberate poisoning. Section g12 is the other or undetermined or unknown cause so if you marked in section f2 is the cause of death is undetermined, other or unknown, or if you marked as an undetermined if injury or medical cause or an unknown cause of death, that will take you to section 12 which is just the narrative but this was not intended to be used.

There is a section, Section M, and can I have the next slide, please?

I have one more slide before I turn this back over and that is section h. Other circumstances of incident. H1a and b are the incident and usual sleep place. Port a crib and pack and play should be marked as a play pen. We are change that go and it will be made online and on our printed forms, it will be changed to mark that as crib. We also have people who are saying they consider a twin bed to be a child's bed and so they put it in as other and what the key to do is select adult bed, and when you do that the skip pattern is going to give you the option of a twin bed. So with that, I will turn this become over.

>> Hi again. While Esther and Heather were talking, quite a few of you submitted questions about the data elements and we'll address that at the end of the presentation.

We realize it's difficult to try to do that in the middle of our discussion so we're going to at the end identify some of the specific questions you had. We have a question saying what is a rollover? What do you mean by that? We'll try to address that when we get to the end. Now I want to talk about our favorite section that causes us the most fits in terms of the technical assistance that we hear from you and the questions that we get and that is Section I, acts of omission and commission. This section really, if you think about it, should be considered for the majority of all of the deaths that you're reviewing excluding your natural deaths. And in some cases you may even want to go to that for your natural deaths. You may find that there was an active of omission or commission in the death of a child who was chronically ill and needed a whole lot of care and maybe the appropriate care wasn't being provided. Then you would definitely go to this section. We found a high level of folks were using it, about 62% of you said you were answering this section. We know you're struggling with it and having some problems. Especially at the beginning of the section. When you're thinking about an account that caused or contributed to the death, I wanted to give you a sense of what the two differences are.

Could you move the slides up a little bit for us?

We can't see the entire slide from where we're sitting if that's possible. An act is a homicide -- an act that would cause a death would traditionally be something like a homicide or suicide which would be the cause or direct cause of the death. But an act such as failing to supervise a child may be an act that contributed to the death so it's really -- it's part of your team discussion to sort of figure out how you want to answer that question. This question is the one place on the form where you can actually provide more information and it's the one place on the form where we're going to learn a lot more about the suicide, the homicides and the child abuse and neglect. This section is really designed

to capture that information so if you don't go there with your cases, we're going to -- we're really going to lose some real opportunities to collect this information. You want to -- the supervision question sort of gets people caught up because a lot of times, one, they don't go to it or two, can't decide whether it's poor supervision or whether it's neglect and that's really something that your team is going to have to make the call on. You want to check poor acts of supervision if you believe it was a factor but didn't rise to the level of abuse or rise to the level of neglect. I've heard some people say it's the difference between an inch, you know, and a foot in terms of whether I was watching my child for a few seconds and left them unattended. We hear people talk about there but by the grace of God, that could have been me with the short lapse of supervision but not up to neglect. That's up to the team to decide how to answer that. If it's a suicide, make sure you answer suicide because that is going to lead you to the entire suicide section. And that's where we're going to get a lot of really rich information on the suicides. The other negligence section which people tend to struggle with is really designed to capture negligence that isn't considered traditionally child neglect and it would take you to things such as vehicular homicide where there was a drunk driving incident that caused a crash or maybe some other types of negligence. Manslaughter where people were doing something pretty negligent that actually led to the death of the child but it wasn't along the lines of child neglect. It may have been negligence on the part of the stranger that led to the death of the child but not necessarily neglect on the part of someone who the child was under the care and custody of, meaning those sort of child neglect definitions. The caused or contributed section also gives people a lot of trouble and I wanted to run you through some specific examples. Cause means something -- somebody did something, an act that actually caused the child's death. Contributed means somebody did an act or an act -- or didn't do something that contributed to the death but wasn't the direct cause and I'm going to give you three examples. Cause, for example, you have a mother who leaves her baby

with a very abusive boyfriend. He has a violent history and maybe she's even been counseled by family members or protective services not to leave him alone with her baby but she does. While she's gone, he kills the baby, perhaps he shakes the baby to death. You would put down that the cause was abuse and it was the mother's boyfriend so when you get to that section about who the perpetrator was, it's mother's boyfriend. Contributed, though, your team may decide that the mother was neglectful because she knew she shouldn't leave the baby with the boyfriend. Then go to the sections for her as a perpetrator under contributed. Another example could be a cause might be a teenager who shoots himself with a firearm but contributed might have been the parent who knew that the child was suicidal, had had a mental health history of attempting or thinking about suicides but they kept locked -- loaded and unlocked weapons in the home. In that case you might think that was neglectful and decide that you're going to list that as a contributing cause. Another example would be you may pick neglect in a situation where a mother or father did not intentionally seek medical care for a child who was ill. They didn't take them to the Doctor, and that they were all kinds of complications with the baby but didn't seek care. You might find out it was because of their religious beliefs where they didn't -- they opposed traditional medicine or had other religious beliefs where it wasn't right for them to go to a physician. You would maybe choose under contributed that it was a religious practice as a contributing cause so that should give you a sense how to use the two columns but have a discussion about which columns you would answer and make sure you follow through on the question when you get to the perpetrators and the whole rest of the questions because it will get you to sections. If you don't answer the questions you're not going to get to the other questions. We've gotten a lot of people, say, on question i11 the distinction between chronic with the child versus pattern in family. And I made this little schematic to show you, when you're thinking of chronic with the child, it's the child themselves. Maybe there had been chronic abuse on the child and so the child had been

abused over a long period of time. That would be chronic with the child but what about a pattern in the family? Or pattern with the perpetrator? That may mean the perpetrator had a long history of being an abuser. You're broadening the world there of the child and thinking about the family. I'm done with the acts of omission and commission. It's not easy. We know you're having trouble with that section but we really encourage you to not pass it by and to trying to that section for almost all of your cases. The next section is Section J. 53% of our survey respondents always try to complete this section which is good news. Bad news is 47% of you are not. We like this section because it should really be an area where you go to to start thinking about what kind of improvements can we make in our community as a result of this death in terms of improving services for the family and community. That's what this section is designed to help you do. It's not just about collecting the information but it's about having you think through what are you going to do differently. Our respondents indicated they frequently don't have this information. Who does the family get services from? Who could the families get services with in the future? What kind of services could your community have in the future? Did the family get services? If they didn't, why not? Because you don't have them available? Is it because referrals weren't made? It's designed to try to trigger you for making referrals for services in the future. 23% of the respondents said they had the information for the section. Try to get more information related to services and beyond just getting information about the circumstances of the death so you're sort of taking it to another level. Next question. We all know that the whole purpose of child death review is prevention and this section k is really designed to kind of help be a guide for you as you're thinking about what you want to do now that you've reviewed the death and have all of this information from SECTION G and A, B, C, D, E, F and G. What do you want to do about it? Only 50% of our respondents said they always try to complete this section. We would really like to find out in a year from now that 100% of you are saying that you always try to complete this

section. What we think happens is that during your review, you get tired out and worn out and you sort of are finished with one case and moving on to the next. We hope you'll be thinking about prevention as the real purpose of doing your reviews and this section can help you do that. One of the biggest areas where people tend to get stuck is question k1. Could the death have been prevented? We know that can lead to arguments and struggles with your team and we know that sometimes people leave the review meetings ticked off with each other because they haven't resolved this question. There's a state that I was recently at where the team had to vote on this question. If the answer is no, they're not supposed to continue doing any more of the review. We're working on that. But we really want you to use this question more as a discussion. It's a very subjective question and it's really meant to help you think through. If you think it could have been prevented, what are we going to do to try to prevent it? Think about it in that way and not get so hung up on the yes, no, maybe so. The other thing is when you're filling out the section on recommendations that the team has identified as a result of the review, try not to put in things that you've already recommended from prior cases. This should be new answers. And you can really use the grid in section k during your discussion to kind of as a framework to sort of figure out what you want to do about prevention. It's really set up that way. We use the injury model to sort of set up how you would think through prevention so use that as a planning grid, not just as a final decision for your team. Now I want to talk about section l.

Section l on the form was really designed, and this is the next slide. Thank you. Section l was a tool for you to sort of have an easy way to do some quality assessments of your own review process and so that maybe once a year you'll go back and review this information and use the answers to help you decide how you want to improve how your team functions. That's important with section l5. Factors that prevented an effective

review. Spend a minute at the end of the review to answer those questions and it will give you some nice information. If you find, for example, that you never have the right team members at your review, it will give you a sense of what you need to get the right team members. If you find that confidentiality is always a factor in your reviews, think about what you can do to get better access to your information or have discussion with folks in your community preventing you from getting that information. Then I6 is the place, we get a lot of questions from people, where do we talk about our disagreements with what we put in the beginning of section g which is the official manner of death. Where do we say we disagree with that as a team deliberation? Well, that's where you go to Section L6. You can say we disagree with what was on the death certificate and gives you a chance to say what you think the cause of death should be.

Next slide is the narrative. As you know, even before we had this system, it's often the narrative that tells much more of the story than the rest of this case report tool. Even a short, one or two sentences can go a really long way to communicate what happened in this case. And it's easy to do. All you have to do is go in and type whatever you think would help embellish what we're missing in the rest of the review. So we really encourage you at every case just to fill out a little bit of the narrative if you think it's going to help us. Or help you, actually. When you pool all of your cases at the end of a year or six months and you see the narratives, it's really going to tell you more than just doing your data analysis. We do want to try to encourage you not to record identifying information in the narrative because when you're doing analysis sometimes that stuff pops up in your spread sheets and what have you and make what you think was a deidentified case suddenly identifiable. Try not to put names and addresses and certain pieces of information that would identify a case. And also, don't redo your narrative as simply as synopsis of what you've already included in the form. The form is designed to get you through some of this

stuff quickly. You don't need to use a narrative to complete what's already in the form. It will save you time if you do that. I'm going to turn this over to Ester.

ESTER SHAW: We would just like to remind you that this is your data and we're hoping that if you use this standardized report, it will help you be able to give some feedback to your collaborating agencies, prevention workers and when we looked at the survey responses, we found that only 40% of the people who responded said they had never used the standardized reports and 40% said that they had used the standardized reports one to five times and that may just be a function of your job. It may be that, you know, it's not -- you're not writing reports and therefore, you never go to that seek but we thought we would do a little bit just to kind of familiarize you with how it works.

If I could get the next slide. This is what the screen looks like. There are 33 reports available. There are multiple filters. Select only on cases completed or all cases. You can do by year of review or year of death. If it's the year of review, it's going to come from the case definition screen. If it's the year of death, it's going to come from section a. You can do multiple years or single years. Depending on your user level, you may find that to the right of each of these items there is just a local report or a local and a state report. For those people who have state permissions, there would be another drop down to the left. And to do the local reports, they would use that drop down beside whether the team or the county, depending how the state is set up, and then press the local and then with case type, that's either a child's death or a near death and if your state does not do any near deaths, then you would not need to worry about changing that. But you'll see that that's the default. And finally you have to have popups unblocked on this particular screen and when you get the reports, there are ways to export the report. You can print the report, you can save it as a P.D.F. and if you need help, feel free to call the national center

because some of the exporting features aren't very user friendly, I mean, as far as figuring out what to do next so we would be happy to help you with that. They can be exported into things like excel. Now we're just going to go through a couple of definitions. This one we put at the end because it applies to so many different sections and it has to do with opiates. Morphine, methadone, heroin, codeine, Oxycontin. Because methadone is now prescribed as a painkiller, and it's a check all that apply, you can check painkiller, opiate and methadone in the same overdose.

Can I have the next slide, please? Since we already went over chronic with child and pattern in family, I'm not going to spend a lot of time on that. Again, that is in the data dictionary. And section j, we would like only if the child -- if the funeral arrangements were provided for the family, this should be checked. Not every child has a funeral.

We will be answering questions at this point but I would like to thank you. I would like to reiterate that if you have any problems with the website or if you have any questions or want clarifications, here is the 800 number on this slide. There's the child death review website. There's our email address. The sooner you can get any website problems to us, the quicker we can work -- we keep a log of all of the problems if you get any errors so the quicker you get those to us and the more often, then the better we can try to change those with our I.T. people. At this point I would like to turn this back to Teri for questions that came up.

>> We got a lot of questions and actually, if you can keep the camera on all of us. In keeping with the difficulties that we know some of you face in answering some questions, we're sitting here having a little difficulty answering them ourselves. But we're going to give it our best shot and tell you what we think and they're kind of scattered around. We

tried to organize them but I think we'll go with you as they came in. Someone wanted us to give an example of where it would be a natural death but you would have an incident. And one of the things we were thinking of would be if the child had asthma, that would be included a natural death typically but if they had an acute asthma attack at school, you would have a lot of information then about the incident in terms of where that asthma attack occurred and you would have an incident there that you could discuss. That's different than a child who is a newborn who is in the hospital. We talked about the incident place then being, you know, the hospital and we're actually thinking in version three on some of those cases not taking you through a lot of other questions on incident where there would be some skip patterns to get you out of answering some questions that don't seem relevant but until version three comes out, you'll have to move yourself through that if you can. We had another question that said what category would maternal substance abuse leading to premature death go in when you're filling out section f? For manner, you should be using the official manner of death from a death certificate. And I have seen deaths of premature deaths where maternal substance abuse was reported. I've seen them called natural death because of premature birth weight. Use what's on the death certificate. Going to cause, I think you would probably going to prematurity but there's also an option which is other perinatal conditions. Specify and go to Section 11. So you have to really think it through as a team. Again, there's no right or wrong answers on some of these and you have to really use your team's discretion. But for manner, you should always be using what is on the death certificate. Another question that we had is that if the death certificate is left blank on manner so it's not listed -- and we see that a lot but it's obvious to the team it was a natural death or accidental death, can't we just put it in and trying to amend the death certificate as our team? At least put it there so you've got it there in the reporting tool and we have it in the reporting tool. I think that's a question where you go to your state coordinator and say what do you want us to do in this situation

for our state? I think that's a question best left to your state administrator. It wouldn't bother us if you did that if it was really clear cut in that situation. If it seems to be a little tricky and you really weren't sure what the manner actually was, you may want to think twice about it. We also had a question about is rolled over in the driveway the same as a vehicle rolling over and sbu the ditch? We've actually heard this quite a few times. There's a lot of different jargon going on in the motor vehicle arena in terms of rolling over -- cars rolling over versus people rolling over on kids. We actually, in this situation, and we noticed it's not clarified in the data dictionary. But a Rollover is actually the car rolling over and a Backover is actually the child being backed over by the car. We actually know now there's also Frontal, kids hit by being in front of a car or a bus or what have you and being hit. We need to clarify but in this definition, rollover is the vehicle itself rolling over and we will clarify that in the data dictionary. Another question about income. How do you define income? When we were building this, we struggled with that question in terms of what is low income, what is medium and what is high. That question is in there as a marker. It's really up to the team's discretion and we know it's a very subjective question. It's really -- the way we define it in the dictionary is really for your team to identify high, medium, low based on the context of your community. Now, that could mean then that somebody living in a very affluent community, low may mean middle for many of us but your team is really going to have to think that through but what we're really getting at is people that are poor versus people that are middle class versus people that are wealthy and that's as good as we felt we could get it. We didn't feel there were any good markers out there that you would have access to information on to try to get better information. There's a couple of places in the report tool where you try to get to income. For example, whether or not the family was on public assistance. That would certainly help identify the family as low income. We really kind of want you to think that one through simply within the context of the community and to understand it's a subjective question. Do you have any -- guys have

comments on that? Do you count it as a crib if they die in the NICU at the time of death so they're in a crib or an incubator is what we're calling these things. The answer would be yes. We decided that the answer would be yes but it makes us think for maybe version three we need to have an I.C.U. bed as one of the criteria but if you actually list the place of death and you clarified that the baby died in the I.C.U. and it's a crib, it's going to work for us when you do your data analysis. We can capture that. When are we going to get new data dictionaries? We want to do a little update to go version two and we'll fix the port a crib, pack and play question and making that for complete and we'll try to fix the rollover question. We've heard that from a lot of people. We'll try to get that to you within the next maybe one to two months, as soon as we can get it taken care of. Someone asked, what about a teenager who was riding with a drunken teenager? How do you answer section i1, I believe? Or is it Section 11? I think they're trying to get to the cause. So if it were me and I were filling out that section, it would be the act of omission. I would say that you probably had a crash so the crash probably was the cause. If you're thinking about whether the drinking -- the drunken driver actually caused the death or contributed to the death, I can't answer that for you. That is where the team should be having a really good discussion about how to answer that. If they felt that it was actually -- you know, the kid was so drunk that they completely, you know, caused the accident or the crash to occur, I may say cause. It really is a decision, though, that your team is going to have to make. Someone mentioned that they never really fill out section j on services because they see themselves as a review team but not as an intervention team and so even if the information is available, they don't fill it out. I think it's important for us when they think about that section that it's not just about interventions for the actual case but also about looking forward and thinking about improving services is an important part of prevention as well. So even though you may not be thinking about interventions in this case, you can think about services that you may have identified as a result of this death that you feel need to be put

in place in your community for future -- for other families and for other community members so it's not just meant as an intervention section but as sort of an opportunity to think through improvements and services in the community to help families in the future. Section k, we heard this question, which is our recommendations rarely result from a specific cause and our recommendations are made over time so how do we handle this? There's actually a place on the report tool where you can check a box saying I want to come back to prevention at a later date. We haven't figured out an easy way for people to do this yet. What it does is require you to go to each individual case but you can do -- on a regular basis you could actually go and do a search for all of the cases where you checked come back to this on a later case and then you can sort the cases if you wanted to in terms of motor vehicle cases or your suffocation and bed cases or what have you and think through if you've actually done some interesting things on prevention, go back and maybe make updates to your specific cases based on what you've done in terms of recommendations. But we know this is an issue with you and we're trying to create a specific module that would capture the recommendations and the prevention initiatives your team has designed in the aggregate, not specifically with the specific case.

>> I think with the C.D.R. case reporting system, it is on -- sorry. It is on an individual basis so we do hit this point and we struggled with it when we did version two and we're continuing to think about it. But at this point if we could encourage you to go back and try and mark your cases in K1 and then when you do data download, you might see the aggregates popping out more readily when you're doing the data download.

>> Someone made a nice suggestion which is if they're checking other, under cause and manner -- or not under manner but under cause and tends to be a medical cause and they don't quite know what to do, ask the doctors and nurses on your team. If you don't have a

pediatrician or medical person on your team, it's time to get one. Sometimes they can really help you decide which category those should be to or how to describe them or how to interpret the medical records and how to make sense of some of the medical language that is difficult sometimes to even read, let alone understand. And someone even suggested using WebMD to decide where it goes to try to get you more information. Some of those deaths come through with pretty complicated words that, you know, we don't know what they mean. So people could actually go to web id, put in the word and it can help you get a better description what the cause was. Someone asked, am I supposed to fill out a report for every death in my county? That's a suggestion that you need to have with your state coordinator. We do have states that even though they don't do a review on the case, they're actually filling out the report form as much information as they have and then you can actually -- we could keep track because of the way the system works and actually ask, when did you do the review? How many reviews were held? We could tell whether or not a review is done on the cases and whether you're just entering cases or information into the cases to have in your data base and we know that some states are wanting to do that because it gives them a chance to keep track of all of their deaths. Have a discussion about how you should handle that question. And then someone asked, is prematurity a chronic disease? And I think the answer to that would probably be no in terms of how you would answer that under cause and manner. Do you guys have a -- it's more of a perinatal condition. In the jargon, prematurity and low birth weight are thought of as conditions in the perinatal period. If they were born premature and nine months later died and it was felt that the prematurity was the cause of it, then maybe it is the chronic disease. The way we're answering these questions makes you realize how complicated some of these things are and it really is a discussion that you need to have among your own team and with the folks at your table and with the medical professionals that are at your time, especially on some conditions related to perinatal causes.

>> I have a question for the team and I'm smiling because the title of our Webcast is Let's Make it Easy. And we see that this is really not easy but it's so critical and so important and all of you as users are so important to our effort to really get a picture of child death review and the system of child death review so here is the question. We are currently transitioning to this system from our old proprietary system. What are the most common and/or trouble some problems that states usually face when they first implement your system, this system? We might have stumped the panel.

>> Regarding migrating the data or just adapting the new C.D.R. case reporting system.

>> What do you guys get as tech requests when people first start using it?

>> I think having to select one supervisor on an issue that came up and how to make that determination. Whether or not information is deidentified before they submit the information. It's not deidentified when you're entering the information online. It's coming to our server fully identified but also the national center. We only have access to the identified data so that I know in doing the data disagreements, that issue has come up a lot. Section i is really -- teams really struggle with trying to answer those questions and oftentimes get tripped up on assessing blame and section i really isn't about assessing blame. So I think that question -- the introduction of that section as a new system might be difficult to new users.

>> And I think the other thing that I've seen is children who never leave the hospital, a lot of questions around who is the supervisor, who is the caregiver, what is the incident, those

are the types of things that I recall as being training issues. And issues that need to be decided among the team.

>> I also find that new users don't usually go and download the data dictionary and the user manual and -- because, you know, once you get into the web based system and you see how easy it is and you think I can handle this. This is pretty easy to do. It is easy to do from a technical piece but answering the questions themselves is not and that's why we really, really encourage folks to use the data dictionary and have a copy at your review meeting if you're struggling over how to answer something and use the user manual. It can give you extra guidance.

>> I think some folks get overwhelmed by the size of the report form. It's 16 pages long. But if you go on to the online system, the skip patterns are built in and you get very fluent - - Stephanie and Teri mentioned we do the online serving in the winter of 2008 and majority of the users are saying they can input a case in 15, 20 minutes and also wanted to mention the results of the survey is available. I think it's somewhere on the web cast link so you can take a closer look at the results of that survey as well.

>> We do find for those of you that are new users that the longer you use this, the easier it gets. And we used to get a lot of help requests from states like Ohio and Pennsylvania and Michigan that we don't get anymore. Once they start using it, they do sort of figure it out. That doesn't mean that there's not data quality issues in those states because there's some inconsistencies and that's what we hope today would help. We had a question related to data analysis. Someone asked, do you have any plans to create reports that, for example, of all children that died in one city or county or zip code or drowned. Reports can be generated with drop down boxes.

>> I think it's a great suggestion and we put it on the wish list for version three. You know, and the person that said we're not data savvy, one of the things we recommend is that as a local team, you have an amazing data base if you've been entering your cases that you can download into access and you could find all of your drowning deaths by zip codes. If you wanted to have your state do that, you could ask for those reports and if you don't have data savviness within yourselves, I'll bet somebody on your team does. I'll bet you have an epidemiologist. Heather and Ester, you may not be savvy but they can show you how to download the data. It's more complicated than doing the standardized reports but it is available and it is doable if that's something that you're interested in doing. We have -- someone asked us what -- with the economics of the day, I don't have the exact question in front of me but is there a concern that with budget cuts and what have you that this system is going to go away. We're funded right now for three complete years and I don't think there's much interest in the bureau of having this go away. Stephanie?

STEPHANIE BRYN: We don't expect it to go away. We expect it to get bigger and deeper and more important to all of us and all of those who care about this issue and the data. There's one more question before we sign off.

>> This is another technical question. For a death of a premature baby at what gestational age do we not need to review a case? That's not for us to decide. That's for your -- either your state to tell you or your local team to make a decision on. You guys should be deciding how you want to use that. I'll tell you, though, the report tool is set up so that you can do death reviews of still births, reviews of serious injuries or reviews of deaths so you can put all three -- or live births so there is an opportunity at the very beginning of the form

to list what kind of death that is but we can't tell you and we really don't want to be in the business of telling you what deaths you need to be reviewing, when, where and why.

>> Another wish list for the team, a couple of blank fields for local use. Otherwise, we have to co-op an existing question or keep a completely separate data base.

>> We get a lot of requests to fine tune the system to put in -- you know, if you're from Muskingum, Michigan. Version three, rumor says that can be done a lot easier to you could do customization by the states or communities by the questions. We're just kind of hoping we get through version two in the next year or two and then need to get the funding to rebuild version three but it will be something we hope to have in the future. There will be more customization. That's an interesting thought of leaving a blank field. Good suggestion.

>> I think we're going to sign off now. We really do want you to fill out the evaluation. It will give us some good ideas. I want to end with a comment that came in from a viewer and I guess it kind of shows how I've been feeling about the work you've done. Thank you, it says. I love you guys. You should see the data I have pulled in from -- I'm going to say it, east Tennessee from the downloaded data and it's signed Judith. We just think this is a great system and we thank you for being frequent users and we thank you for attending our web cast today.

>> Thank you.

>> Have a great day.

>> Bye.