

MCH/CSHCN Director Webcast
Preventing Child and Adolescent Deaths:
Resources and Partnerships

December 14, 2006

DAN KAVANAUGH: Good afternoon, welcome to our webcast on preventing childhood and adolescent death resources and partnerships. The moderators are Captain Stephanie Bryn, and myself, Captain Dan Kavanaugh, director of the emergency medical services for children program in HRSA's child health bureau.

Slides will appear in the central window and will advance automatically. Changes are synchronized with the speaker's presentations. You do not need to do anything to advance the slides. You may need to adjust the timing of the slide changes by matching the audio using the slide message delay at the top of the window.

We encourage you to ask the speakers questions at any time. Type the question in the white message window on the white of the interface, select question from speaker from the drop down menu and hit send. Please include your state or organization in your message so we know where you are participating from. If we don't have the opportunity to respond to your question during the broadcast, questions and answers will be posted along with there webcast when it is archived. Again, we encourage you to submit questions at any time during the broadcast.

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Those of you who selected accessibility features when you registered will see text captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple minutes to do so. Your responses will help us to plan future broadcasts in this series and improve our technical support. Now I would like to introduce our first speaker this afternoon, Dr. Brian Johnston of Harborview, Seattle, Washington.

BRIAN JOHNSTON: Thank you, Dan. Thank you all for tuning in on this mid December day to talk about preventing child and adolescent death. What I'd like to do by way of overview is to talk a little bit about the concept of Child Death Review and explore the potential for preventing. And then barriers that may exist in the Child Death Review process to limit the ability of teams to do injury prevention. I would like to describe our recent grant funded efforts, to identify strategies and solutions to overcome the barriers and allow effective prevention in Child Death Review. And finally, the planned dissemination of tools and resources that may assist the teams in building the pathway to address injury prevention. As many of you are aware, Child Death Review developed in this country in the 1970s. Idea to have multi-disciplinary teams formed initially to assist coroners or examiners to understand the concept of child death. The primary goal was abuses or intentional child deaths were not misclassified as SIDS or some other natural cause.

Today child deaths is reviewed, at least some in every state and the district of Columbia, increasing the proportion of deaths in this manner is the goal for 2010. [Inaudible]. In most cases the team will include a coroner or medical examiner, a representative from child protection, representative from the prosecutor's office or law enforcement and some member of the public health community. Expected outcomes of the child death review process are first to insure complete and adequate investigation of unexpected child death. And many cases, promote and provide services for bereaved families. More recently, however, the focus of Child Death Review and the teams has broadened to include prevention activities, asking the question could this death have been prevented and what could we do as a community to ensure that death of this nature or similar does not occur again in the future. Child death review and injury prevention are actually potentially very good, very good match.

Injury, as everyone knows, is a major cause of mortality in childhood of 13,500 childhood deaths in 2001, for example, over half of these were due to unintentional injury, by far the largest cause of mortality. It is the leading cause of child death after infancy. Child Death Review teams have access to much richer data sets than can be reflected in vital statistics or other aggregate forms of data. Child Death Review teams operating at a local level can dig deeper to understand the context and the circumstances around and you think -- unexpected child death and find the more distal causes of the death. Because they operate on the local level, in a better position to understand and appreciate local resources to help prevention. Child Death Review to be a driving force behind injury

prevention activities at the local or state level. Many see the outcome to date as an unfulfilled promise, given the enormous contribution to child mortality in this country, more engaged in injury prevention at some level. To be sure, there are good examples of local teams effectively addressing it in their community, but also clear reasons why this doesn't occur more broadly.

The barriers in the Child Death Review process include, the next slide, inadequate data.

This is because death scene investigation typically conducted to verify the manner and intent of the child death. Many of the data elements you need to understand prevention opportunities are not routinely collected in the time of child deaths. If they are collected, the agencies or individuals who have access of the data may not be represented on a typical child death review team, so that at the time the death is discussed, no one has access to the information needed to make reasonable prevention recommendations.

Another barrier is, exists in the forms of protocols that many child death review teams employ. Data collection forms are designed to be concise. Lots of fields to fill in or boxes to check. But they tend to lack the specificity that is required for prevention-oriented review. Only so much space that can be taken up, particularly on a paper-based form, and the data elements that the team has prompted to collect may not match those required to do good prevention. Data collection forms also have a limited amount of space typically for a team to enter prevention recommendations. A good prevention recommendation, as we will see later, may require several pages of detailed analysis and recommendation, and that is not available on a typical data collection form. Turning to the protocols of the child death review team themselves, it seems self-evident but in order to do good prevention,

Child Death Review team needs to have the review process to discuss prevention steps. Often this isn't the case.

Another barrier is a membership of the team itself. Many teams were originally convened to perform an investigative function. They do not necessarily have members on their rosters that are familiar with the public health approach to prevention. They may lack the skills or the connections needed to translate prevention recommendation into action.

Another barrier identified in conducting good injury prevention through the Child Death Review is lack of expertise and leadership on specific teams. Most local teams don't have the luxury of including an identified practitioner, so even teams that want to be prevention-ore -- oriented may not have access to the latest research. As a result, some prevention recommendations generated are too global, vague, or do generic. Recommendation, for example, that people should wear seat belts may be true, but it doesn't translate very well into policies or programs that Child Death Review could promote. And we have learned over time the coordinators are crucial in motivating the prevention focus on their teams. Teams that have motivated and experienced coordinators tend to do a much better job at developing the actual recommendations than those whose leaders are inexperienced or relatively new. Turnover in this position is not uncommon and most team leaders are not specifically trained in prevention practices, they are skills they have to develop over time.

Another barrier in preventing or in, to injury prevention in Child Death Review is a focus on the concept of preventability. Off and on the structure data entry forms teams are asked to assess the preventability of a specific death. What this means isn't always clear. In many

cases what a team is being asked, can you identify prevention that might have been achievable through optimal functioning of our public agencies, coordination of public systems or coordination of public policy. And if the team does not agree that a death may have been preventability through one of those mechanisms, then the death is deemed not preventability in that sense, and broader options for injury prevention in the community as a whole are put aside. Yet another barrier to injury prevention and child death review that has been identified is accountability.

In many jurisdictions it's not clear to whom prevention recommendations are going to be directed. Does the team report to the health officer, to the board of health, to the general public? Certainly that would determine the scope and content of the recommendations made. But it's not always evident at the local level who is overseeing a given team. It's also obvious that in many cases completion of a data form and submission of data to a state repository can overshadow the local flavor of Child Death Review and become a goal of the process in and of itself. In some ways this advocates the Child Death Review, a very rich discussion of the context of the circumstances of child death and boils down Child Death Review to something akin to glorified vital statistics reporting. When teams focus too much on data information, then local action on local issues is forfeited, the goal and outcome of the process.

Finally, funding and the mandate of teams. Teams are typically only funded for information gathering and symptoms if they are funded at all. And in order to be able to effect prevention, they need to be able to coordinate with other agencies that have the resources

to take prevention recommendations into action. Similarly, the teams mandate legally may specify investigation, but not prevention and present a barrier to teams seeking additional funding for those programs. The next slide, we were able based on identification of the barriers that were just discussed, to propose a demonstration project, to increase the quality of injury prevention recommendations made by Child Death Review teams, expertise on local teams, to identify strategies to overcome barriers to prevention-oriented child review. And the decision that would allow Child Death Review teams to act best practices in injury prevention. Currently we were fortunate to receive funding through HRSA and EMSE targeted issues grant program 2004-2007.

The focus of our capacity-building activities has been technical assistance, training, and the development of decision support resources. The partners on our grant are five Washington state local Child Death Review teams, Franklin, Seattle, and others. In addition, we have worked with the Washington state Department of Health and the national MCH center for Child Death Review. Colleagues at the Harborview prevention and research center have partnered as well with health educators at Seattle Children's Hospital to develop the technical resources. The grant activities to date have included identification of injury prevention liaison, each of the partner teams, series of technical assistance teleconferences, where written the -- we don't propose to tell the teams how to run their Child Death Review process but have invited teams to discuss these barriers to conducting effective injury prevention and then share with their colleagues strategies and tactics that they have developed to overcome those barriers. Local teams turn out to be a rich source of this information and we have been pleasantly surprised at the amount and

depth of information that we have found on the ground at the local level. We have also scheduled a series of in-person conference days for our grant participants, and sponsored professional development for selected team members. Finally we have spent time and energy developing web-based resource for best practices and injury prevention and geared toward the child death to be processed. I'll discuss that in some detail later.

So what have we learned to date? Well, I'd like to review that with you now for the next 20 or 10 minutes. Talking about some of the strategies that we have identified to promote effective injury prevention in the context of Child Death Review. And also talk about our plans for the resources for Child Death Review teams. The strategies to facilitate effective prevention in Child Death Review really parallel the barriers that were identified earlier. Some of the strategies may seem self-evident, others are novel and ingenious. The first strategy is accountability. It goes without saying that for a Child Death Review team to be effective at promoting prevention, they really need to explicitly identified prevention as a goal of that. Surveys suggest that most Child Death Review teams and most Child Death Review team members strongly support the concept of prevention and identification of prevention opportunities, it's important the teams acknowledge that up front. It's also important that local teams understand to whom their team reports and how their efforts will be tracked over time. It's important because you want your sponsor to support your identification of prevention as a goal for the child death review process in your community.

Another strategy to facilitate effective prevention in Child Death Review, revolves around the member shiepl -- membership of the team. It's important the teams mature, that their

membership expands beyond the investigative focus that determines membership early on in the Child Death Review movement. So in addition to the prosecutor, coroner, child protective services, you want to add experts from your local community that have some facility with conducting prevention and understanding the information required to generate good prevention and recommendation to develop prevention programs. Many teams have a fluctuating membership, they will invite additional members for specific Child Death Review when they recognize that experience in a particular area is needed. For example, a suicide prevention expert may not be at every meeting, but when it's discussed, she will be invited at that meeting to lend her expertise.

Another strategy that teams have used, replicate, I believe, a structure that exists in the fetal and infant mortality review process, concept of a prevention action team. That is Child Death Review teams continue their investigative process trying to understand what happened and then turn their findings over to another team, prevention action team that can take the findings and turn them into prevention action or recommendation.

Membership of those two teams may overlap, but the important thing is that the prevention action team includes members that are, hassle with prevention and prevention-related activity. That team is charged to act on the recommendations that are generated by local CDR. Another strategy to facilitate effective Child Death Review revolves around developing expertise. We found that just identifying the team member as the injury prevention expert is very useful. Not necessarily people who have had training or background in injury prevention, simply a team member who has an interest in injury prevention, motivation to pursue additional training in injury prevention, and a willingness

to function as the team's resource for injury prevention. Clearly local expertise can be developed through training, but expertise can also be shared between local teams.

Many county teams are relatively small and meet less than monthly. It's conceivable that an injury prevention expert could meet with a local team or a series of local teams on a rotating basis. Sharing the expertise is one way to make limited resources go further. We are also interested in promoting use of web-based resources, increasingly prevalent and can be very useful, rapidly developing injury prevention expertise. Next slide is a duplicate, if you could forward through that. We'll move on to discussing the concept of preventability. And it's how we can use that to facilitate effective prevention in Child Death Review. We would really recommend based on our experience with local teams that you minimize the discussion of preventability. In reality, no death in any team review is now preventable. But we know most injury deaths have aspects of preventability, and should be considered preventable. But a team gets bogged down in discussions or arguments about preventability, the discussion is often non-productive and may lead to teams to spend a lot of time and not generate a good recommendation for what would be a relatively preventable injury prevention or death mechanism in that community. Again, this reflects the need for teams interested in prevention to shift from an investigative focus around trying to determine what happened and whether this particular death was preventable, to more of a prevention orientation.

Another strategy employed by many of our teams to facilitate effective prevention is to group death reviews by mechanism. This is particularly useful for teams that review a

smaller number of child deaths. And what it means is that teams will set aside a meeting to look at all the motor vehicle related deaths. For example, the suicide. Not every death received in isolation could generate a full and complete recommendation. But when deaths are grouped together it's often easier to see patterns and priorities for your own community. And it also allows you to capitalize on the expertise of your membership. Again, you can bring in members to attend reviews when their expertise is most relevant. Using youth suicide example again, if you group the youth suicide deaths together for review, that would be the data to suicide prevention experts to understand and explain the patterns in the community, resources available and to help teams identify potential prevention priority.

Another strategy to facilitate effective prevention is really to push the membership to be prepared. Most child death review teams rely on volunteer participation by representatives from a number of community agencies. These are typically very busy, but also very talented professionals who recognize the value of the Child Death Review and are willing to give up some of their time on a regular basis to participate in this process. You really want to make sure that you get the most bang for their buck, and ask members to arrive prepared to contribute as much as they can to the discussion. To do so, many teams share detailed information before the actual child death review meeting. Much is known about the cause and circumstances of a given death, shared with the membership so that they can look into their own agency records, they can pull up relevant policies or programs for discussion. In essence, we expect members to do a little bit of homework and come to

the meeting ready to discuss what they have learned. With Child Death Review coordinators, also make a phone call to a member to make sure they show up prepared.

Another strategy that many teams use is really to push or to press for prevention-related data at each discussion. So you want to make sure that agencies or individuals who may have access to prevention data elements are going to be at the meeting and bring that data with them if they have access to it. If you find that you are having problems getting data from a particular agency or a particular group of individuals in your community, you can invite representatives who have access to those data to your meetings to see how the data are going to be used in generating prevention recommendations. It's also important to note in your reviews that your standard data collection instruments or the minutes of your meeting when important data are missing and you can look for patterns over time to understand where you might want to work within your community to get access to the kind of data your team needs to do good prevention.

Another strategy to facilitate effective prevention is to push teams to create an effective recommendation. There is now a good deal of work in place understanding what it takes to make effective prevention recommendation. We were fortunate on our project to work with the California state Department of Health, they spent time and effort developing a template for making effective recommendation in the context of Child Death Review. A good recommendation ought to include a statement about the problem that you're hoping to address and the context in which it occurs. It may include reference to local data as well as national data to understand the magnitude of the problem, and it's particular

manifestation in your local community. It also needs to include reference to best practices across the spectrum of prevention. This really requires that you tap into some injury prevention expertise to understand which injury prevention programs or strategies are evidence-based and have been tested in communities like yours.

Recommendations also have to specify the next steps. They have to say who is going to take these steps. To whom are our recommendations being addressed, and when are we going to follow up to assure that something has happened with the recommendation that we have made. In the next slide we reference the use of a template. There is a sample prevention recommendation generating template on the mchcom.com website for this web cast that you welcome to download and look at. The use of a template pushes teams to address all aspects of making an effective recommendation. We can't overemphasize the need for teams to follow up. If you've made a recommendation to an agency or an individual in your community, it's important to keep track of that recommendation. To go back and make sure that something has happened to it. It is easy with child death review to consider a case closed and to move on, but there often are action items which are outstanding and will carry over from meeting to meeting. That's why we recommend keeping meeting minutes, in addition to any structured data collection or reporting tools that you use.

We also recommend as a strategy to facilitate prevention a relationship with your local media. Clearly there are tremendous barriers around confidentiality, inviting the press into a child's death for discussion. But what you will be aiming to do is to illustrate the review

process in and of itself. So that your community and the media in particular can understand what Child Death Review is, and why it is conducted. It's also very easy for Child Death Review teams generally to provide data and a generic prevention recommendations for specific injury mechanisms to your media contact. And also gives you an opportunity to highlight any policies or programs you may have developed as a result of Child Death Review. Finally, one of the strategies that are teams have developed over time is to keep Child Death Review visible in your sponsoring agency.

Annual reports of your Child Death Review team's activity could include process measures such as the membership of your team, the meetings held, the hours of professional time donated by your membership. You can also highlight specific recommendations that you would like to focus on, or bring to the attention of your agency. In particular, we'd to encourage teams to focus on any measurable outcomes that may have changes as the result of their activity. In addition to written reports, your team should also consider making presentations to the health officer, child protective services in your community, the board of health, or any other sponsoring agency that may have an interest in your activity. So transitioning now to the next slide.

We want to talk about resources for Child Death Review teams. Both existing and those that are in development. I believe other speakers will touch on this, but I do want to call to your attention the web site for the national MCH center for Child Death Review. This has been extremely useful to our local teams as we've worked with them, trying to develop their prevention capacity. Not only does the site and materials include model legislations,

but there are policies and protocols for conducting effective Child Death Review meetings. All of which is online at the web site shown there. As part of our grant activity, we're also developing an online decision support tool with an injury prevention focus. The next slide details how this was developed. We undertook a systematic review of injury prevention for five common death mechanisms or intents. Those include drowning, motor vehicle occupant injuries, injuries related to firearms, deaths due to suicide, and deaths due to interpersonal violence. With each of those categories our team identified strategies likely to be considered or promoted by a public health focus Child Death Review team. Through a process of systematic review and consultation with identified experts around the country, we have rated the strength of the evidence surrounding each intervention to try to identify what would be the best practices and to make those best practices available to local Child Death Review teams through a web based interface.

On the next slide, the online decision support site is a real-time web interface that we have encouraged teams to use during the Child Death Review session. Teams are able to sort the interventions that we have evaluated according to the death mechanism, our rating of the effectiveness of each intervention, the populations targeted by each intervention, or the strategy employed in each intervention. (Inaudible) (Inaudible) -- resources for teams to replicate that intervention in their own community. This is probably best illustrated by an example. Consider a child drowning death. A relatively common death mechanism here in Washington State. A three year old child pulled from a neighbors pool is brought to the attention of Child Death Review to understand this unanticipated child death. Using

the web based decision support tool, the team is able to review strategies by both age of the child and the evidence rating supporting the intervention.

The next series of slides are screen shots from the web site. They may be difficult to read, but I'll point out the key features, so you can get an idea of how this web site will work when it's employed in practice. On slide 34, the best practices drowning site allows teams to select in the upper boxes interventions that are rated as recommended and that apply to the population defined as young children. On the right hand side of the screen, the search results yield only one return, the intervention of pool fencing. This is the one strongly recommended intervention to prevent drowning in young children, based on our reading of the available evidence. For this team, for the purposes of discussion, let's assume that pool fencing and inspection are already in place in their community and they are looking for another idea. Someone on the team may ask, what about promoting swimming lessons for pre-school aged children in our community. Could that have helped this particular child and is it something we as team should pursue?

On the next slide, you see that the team has selected interventions of all ratings, not just those that are recommended. You can see a list of perhaps 15 or so on the right hand side, including the intervention of swimming lessons, which we reviewed as part of systematic review of the literature. Clicking on that link opens another page which is shown on the next slide entitled Swimming Lessons which describes the concept of the intervention of swimming lessons or promotion of swimming lessons as a way to reduce the risk of drowning in young children. We identify risk and protective factors targeted by this

intervention, key features of the intervention, and if you scroll down the screen, you could see the results of our evaluation. But in the upper right hand corner where the arrow is, you can see that we have classified swimming lessons as an unproven intervention. What does that mean? It doesn't mean that we don't think swimming lesson work. Simply, that in our review of the literature, we don't find sufficient evidence.

The next slide gives our definition of unproven. We say that there is insufficient evidence, available to date, regarding the efficacy of this intervention. It should not divert time or resources from other proven health programs. Agencies should ensure a careful evaluation of the program is conducted and disseminated in order to keep it as available evidence. In other words, we are not suggesting to local Child Death Review teams that promoting swimming lessons in their community among preschoolers as a way to reduce child drowning, shouldn't be pursued. But that if they, for example, didn't have a pool fencing ordinance in place, that might be a better way to spend their time and energy starting with promotion of the most promising or recommended intervention. As noted in the slide, if a team decides to go ahead with the swimming lesson promotion intervention, I'm sure it would be nice if there were concessions made to actually try and evaluate them. So we can learn more about what works and what doesn't work in the injury prevention.

Next slide, though, shows the teams ongoing consideration of this particular death, recognizing swimming lessons may not be the way they want to go, they have gone back and chosen the rating of promising rather than simply recommended. Again, limited to the population of young children. This search yields five interventions highlighted by an arrow

there is age one, the team might consider which is a promotion of community-wide CPR knowledge. As they click on that, the next slide shows a number of subsections from the mechanism specific web page, and intervention-specific web page, so that they'll pull up a page actually reviews our findings as a way to reduce mortality from drowning. This slide entitled evaluation and outcome is a summary of the available evidence that led us to call promotion of CPR training in a community, promising intervention. On the next page there are targeted questions for a Child Death Review team. We have entitled this would this intervention be appropriate in our community.

For any promising or recommended intervention, we invite teams to consider some generic questions about their community as a whole, but also incident specific questions regarding the drowning they are investigating. Some of the prevention sensitive data elements that may not be routinely brought to the Child Death Review meeting include, including in this case what proportion of community members have received training in CPR, what proportion of parents, proportion of private pool owners, and among those with training, what proportion has had a course in the last two years, does your community have a resource for CPR training, and then these specific questions. Was CPR administered prior to the arrival of staff, was CPR stopped, what was the reason, if it was not applied why not, a lot of information that may or may not be available in the discussion of a specific child's death, but we believe these questions are asked routinely that information will be available over time.

If the team chooses to pursue community-wide CPR training as an injury prevention or drowning prevention option for their community, the next slide shows another section on the same web page blown up so you can read it, called additional information and ideas, and this provides web links to agencies that offer resources for communities that want to train the general population in CPR. The next page is it shows a link to the recommendation generated. This is, this is the downloadable document that is also on the mchcom.com web site. It brings up a PDF document with forms enabled that prompts the team that wants to make a recommendation, prompts the team to answer some of those specific questions and categories of information that are needed to really generate an effective and meaningful recommendation. So what is our team's experience been with the decision support site? In general I'd say it's favorable. The five grant partner teams have been using the resource for over a year now. The feedback we have received is generally positive.

Teams have requested we add more injury mechanisms in addition to the five that we have already developed. And teams have indicated that there are -- there are difficulties transitioning back and forth from injury specific discussions to discussions of a child injury death or child death due to SIDS or natural mechanisms. And because infant death is so commonly discussed in child death. We add similar best practice review for SIDS, something we will work on. And finally, they have suggested that the site will be more user friendly if there was some linkage to other programs in the review session. Many of the teams used computer or web-based data entry forms during their review to collect child

death review specific data fields, and would like the opportunity to -- to have linkage between this web site and those data entry forms to facilitate their easy of use.

On the next slide we talk about disseminating the decision reports. We tend to make it available for other teams at the end of the grant cycle, at the end of spring of 2007, and we identify a home for updated and expansion of topics. We are very strongly considering and would like to pursue linkage of this web site to hold the repository, which will be discussed subsequently in this webcast. Finally I want to mention our strategies for evaluating this grant. We are certainly conducting some process measures. We are serving our participating teams around their satisfaction, the satisfaction in self-efficacy, and participating in the technical assistance and the best practice dissemination grant, and with the help of Washington state Department of Health we are looking at the completed quality of injury prevention data and recommendation submitted to the registry, the 19 comparison teams before and after design.

So, the lessons learned to date on our grant are, as you might expect, child death review can be for injury prevention. Most teams, though, have encountered some barriers or meet their resources of limit to effective injury prevention on their team, but there are a variety of creative and reproducible strategies that have been developed at the local level for overcoming the barriers. The strategies and resources really need to be shared widely to promote the full value of CDR and that's going to be the focus of the remaining grant. Thank you very much.

STEPHANIE BRYN: Thank you Dr. Johnston. I'm Stephanie Bryn from the Maternal and Child Health bureau here at HRSA. It's my privilege and pleasure to introduce our next speaker, now to the East coast and the eastern shore of Maryland, hear from Sara Rich, the Associate directory of Child Death Review resource and policy center.

SARA RICH: Thank you Stephanie, and thank you, Brian, for the excellent presentation. As Brian mentioned, a barrier to injury prevention in Child Death Review is inadequate data. And this is designed to help overcome the barrier. Child Death Review adds to the existing knowledge of child mortality. And it goes well beyond what is available through vital statistics data. And often times it supplies information that's not available from any other source. That's why utilizing a data tool is so important. Teams may have a wonderful discussion and come up with strategies for prevention but need to have a mechanism to track their review data over time. The purpose of Child Death Review case reporting is to collect, analyze and report on everything from the child's background and family history, to the death investigation, services, risk factors, recommendations and actions. It's also important to document any factors that affect the quality of a case review. For example, if a team is having trouble accessing information due to confidentiality issues and they are documenting this, they may be able to use that data to advocate for policies or legislation that reports the sharing of information in the Child Death Review. And that system allows the teams to do that. Next slide, please. So where are the states in terms of Child Death Review data collection?

44 states have a state report tool. 18 states are required to do that by legislation. But there's really no consistency among the state case report tools or the state reports. So it makes it difficult to pull together information across states, for federal law making programs or funding, or information is consistent. So in response to Maternal and Child Health bureau, created the national center for Child Death Review, serves as a resource center for the programs. Included in the goals is the standardized protocols and materials, a report tool and data system. In order to develop the case reporting system, we brought together a work group of 30 people representing 18 states that met over a two-year time period, looking at the existing state case report form. And what they developed was standardized data elements, a data dictionary and standardized reports available through the web based system through registered users. And I wanted to mention the paper copy is available on the web site for you to download. Next slide, please. Right now there are 15 states that are using the multi-state Child Death Review reporting system. We just received sign data use agreements from Wyoming and Arizona, they'll be joining up soon. The states in the blue on the slide are in discussions about joining up in the system, so stay tuned, we'll probably have this map change pretty quick here. The next few slides are screen shots of the web-based system. The one you see here is the welcome page of the main menu of the report system that a registered user would see once they have logged in. On the right side of the page there is information about the state's Child Death Review program. And then on the left side there is the navigation menu for the system. So you can enter a new case, search for existing cases where you can add or delete if necessary. We have two new functions that are going to be up and running on that search site where

the users will be able to search by all cases of cause or manner of death. Standardized reports can be created and data can be downloaded. Then there is the help section.

Next slide please. This is a shot of a standardized report menu page, and predefined reports that can be generated instantaneously. Local level users are only able to run local reports for their county and their teams. And state level users are able to run local reports for all teams in their state.

Next slide please. This is an example of the help page. At the top there is contact information for the national center for Child Death Review. We do provide training and technical assistance to users of this system. And the last section is the supporting documents that users can download, so they have information on how to use the system, there is the data dictionary and the code book for the download mechanism. Next slide, please. So there are several benefits to state and local teams that use the Child Death Review reporting system. First of all, many teams don't have a comprehensive data collection system in place. This provides a mechanism for that. A risk factor information is collected through this system, so that information can be used to identify prevention strategies, registered users of the system can easily print the standardized, and states can download the data sets in live time, to run frequencies, which is important when they are putting together a media campaign or annual report. What we are really talking about here is the power in numbers, and the power in collecting the same sort of information across the board. When the local teams are collecting the same data, more of an impact at the national and state level. Ultimately it could lead to funding by areas identified by Child

Death Review, such as an injury prevention, Child Death Review and legislative support, and hopefully further collaboration with other organizations.

States using the system are going to be gaining visibility for their work and for their kids.

Next slide, please. And where the rubber hits the road with Child Death Review, the translation of Child Death Review findings into action. A question we ask is if their Child Death Review programs are leading to change. And the past year 33 states reported that the reviews have led to changes in legislation and policy. 32 states reported that the reviews led to actual prevention programs. So that is great news. And there have been hundreds, if not thousands of child health and safety initiatives implemented as a result of their review process. Some are simple, like a community media event or the placement of a road sign, and others are a lot more complex, like a statewide campaign or a state youth suicide prevention plan. And the slide here shows some of the print resources that have come out of Child Death Review teams across the country.

This slide shows our contact information. We have a 1-800 number. An email address. And a web page. ChildDeathReview.org. And if you want more information, please visit our web site and click on the state spotlight button. We have state profiles on every program across the country with contact information so that is available to you. And if you would like to review the case reporting system that I mentioned today, please either call us or send us an email and request a user name and password and we would be happy to provide you with that so you can review our demo site. Thank you very much.

DAN KAVANAUGH: Thank you very much, Sara. This is Dan Kavanaugh. And we have time for actually two questions I'm going to give one to Brian and Stephanie will give one to Sara. The question for Dr. Johnson is where is the online decision support tool and is it available to other teams?

>> Right now the online decision support tool is still in what we consider a developmental stage, so we are sharing it with our grant partner teams with the goal of making it available to the public later in 2007 when our grant activities are wrapping up. Ideally as I said earlier, it will be linked from the national center for Child Death Review home page so they'll be easily accessed by any users around the country. It's currently housed at the University of Washington where our grant is based. But it's not publicly available yet.

(Inaudible)

>> The audience and the participants, the process that you use to create the manual that your great research center has created, and the process that you use to create the web tool? I know there were numerous hours of conference calls and I wonder if you would describe that, please.

>> Sure. Well, the processes were pretty similar for both of those. It was really important to us to engage the state Child Death Review program coordinators and leaders because they are out there doing the work and will interact with the local teams as well. Basically we recruited Child Death Review leaders to join up, and volunteer their time and let me tell

you, they volunteered a lot of it. They met over two years and that was to develop the data dictionary and the data elements, and we just finished reviewing feedback from an assessment that we conducted in the spring with that data work group. So they were back up and running and meeting on a weekly bases for about, gosh, two and a half months. The manual was pretty similar. I wasn't with the center the time the manual was being constructed but I know they also met weekly and the chapters in that manual were authored, for the most part, by Child Death Review coordinators in the state. So they volunteered for the subject areas they know the most and that's really the process that we used for that, and all of the resources that we have, the materials, we really, you appreciate the feedback and the work they put into that. So, Thank you.

>> Thank you. I would like to thank both of our presenters. Please, participants please remember to do the evaluation at the end of the web cast. Many questions were sent through we were not able to get through. We will discuss those with the presenters and the answers will be archived at www.mchcom.com Along with the archive of this event. Thank you very much.