

## **MCHB/ DHSPS November 17<sup>th</sup>, 2004 Webcast**

### **Issues and Strategies for State SIDS and Infant Mortality Programs**

PAUL RUSINKO: Good afternoon. Welcome to the Maternal and Child Health Bureau's Division of Healthy Start and perinatal services webcast. I'm Paul Rusinko and a project officer for the Division of child health and the director of MCHB Sudden Infant Death Syndrome program. The title of this webcast is partnership to reduce the risk of Sudden Infant Death Syndrome. Before I introduce the speaker I have general instructions. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentation so you do not need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. We encourage you to ask the speakers questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu and hit send. Please include your state or organization in your message so that we know where you are participating from. The questions will be relayed onto the speakers periodically throughout the broadcast. If we don't have the opportunity to respond to your questions during the broadcast, we'll email you afterwards.

Again, we encourage you to submit questions at any time during the broadcast. On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon. Those of you who have 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'll have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your response will help us to plan future broadcasts in this series and improve our technical support. Thanks and please let me know if you have any questions. At this point I would like to introduce our speaker and presenter, and this is Lori Cooper, who is the executive director of the national SIDS and infant death Project IMPACT.

LORI COOPER: Good afternoon. I would like to thank you the Maternal and Child Health Bureau. We'll look specifically at issues and strategies for state SIDS and infant mortality programs. There is so much going on in the field. Today research, outreach to new audiences, development of professional standards and bereavement counseling and these are just a few of the things happening in the SIDS community. We thought it would be helpful to try to pull them together and look at where we have come and where we're going. So my purpose today as the director of Project IMPACT, which is a partnership between the Maternal and Child Health Bureau and the association of SIDS and infant mortality program is to give you an overview as carried out by four national programs of which Project IMPACT is one. Before I do that, I wanted to quickly recap the last webcast presented by Dr. Maddox and building partnerships. I wanted to help you understand the relationship in working on SIDS and infant death. The -- both agencies use the definition of SIDS developed in 1991. That definition is currently being studied and revisions are under consideration that would include sub categories based on certain features, consideration of risk factors and other available clinical information, and Henry Krauss's

article on how they're looking at these sub categorizations was just put out in pediatrics this year.

If you want to look at that more closely contact our resource center and they'll help you find that article. Both organizations have launched educational campaigns on back sleeping. The NICHD has had the national campaign. The bureau has been a partner in that as well as supporting many back to sleep campaigns at the local and state levels. Next slide. Here is the history of the first national campaign on back sleeping launched in 1994. You can see there some of the many partners. NICHD lined up a coalition of partners including ASIP, Maternal and Child Health Bureau and public health service. Next slide, please. Tipper Gore later became the spokesperson for this campaign and it picked up corporate partners including the parent company of Gerber so your baby could read about back sleeping while reading rice cereal. That's a joke. The campaign continues with the population of highest rate of SIDS deaths, African-Americans and American Indian, Alaska Native and we'll be talking about that more further in the presentation. Next slide, please. The campaign as I think everyone knows at this point, we hope everyone knows, was hugely successful and reduced the rate of SIDS by almost half. That's the rate of SIDS in the United States. Next slide, please.

There is still a lot of work to be done. Here are samples of the latest literature developed. Assisted in the creation of the African-American back to sleep kit and funded by NICHD to conduct trainings for African-American civic organizations that have helped the campaign to really penetrate hard to reach communities. You can read more about that African-

American outreach initiative in the inaugural issue of the NICHD community connection which is available on NICHD's website. It's downloadable in a PDF format. Next slide, please. This is a bus transit poster from a campaign last month in Washington, D.C. for national SIDS awareness month. The NICHD is going strong. They have recently begun funding for research into still births as they expand looking at other infant death. They've done a great job with this national education campaign and the bureau has been proud to be a partner. Now we want to look at the work being done in the Maternal and Child Health Bureau on SIDS and infant death. Next slide, please. This slide is to show you where the action is in the bureau. The SIDS and infant death programs are located in the child and family health and this is how they got there. In 1974 the Sudden Infant Death Syndrome Act authorized the secretary of HEW, to have counseling by families of SIDS death and December emanate information relating to SIDS in Health and Human Services professionals, etc.

That continued and in 1979 the SIDS program office was established in the Office of Maternal and Child Health Bureau. In 1981 OBRA, omnibus reconciliation act put SIDS in the hands of the state during the Reagan administration. Next slide, please. When OBRA was implemented SIDS services were one aspect of a series of services that MCH Title V directors were expected to deliver to their states. And this included -- I'm not sure how much people can see on their slides but it included direct healthcare services, enabling services, population-based services and infrastructure building services and SIDS, of course, falls under the population-based services. There was not a mandate to have SIDS services, it was up to the states based on their needs assessment and data. Next slide,

please. The way that this would be evaluated is under the Healthy People 2010 objective to reduce post neonatal deaths and states could include their strategies with SIDS. SIDS numbers have diminished. But risk reduction education are often incorporated into other services by health departments, hospitals, Healthy Start programs and so forth. Next slide, please.

Our purpose today is to help all of those who are providing these bereavement support and risk reduction services and the research on SIDS and infant death to see where you can get support for your programs from the bureau. The bureau since 1979 has developed four national programs to support state SIDS and infant death services starting with the resource center that year in 1979 followed by the program support center in 1998, the National Center for cultural competency in 1998 and Project IMPACT last year in 2003. They all work together to provide states with resources for parents and professionals and a wide range of technical assistance to sustain their programs. Don't worry if you can't keep the centers straight. We all work together. If you contact one of us, we'll get you to what you need. Now, I thought it might be of interest that the program support center is located in Baltimore, and the resource center and the cultural -- the Center for cultural competency is located in Georgetown, Washington, D.C. And Project IMPACT and resource center are located in McClain, Virginia. This is to introduce you to each of the centers by letting you know what kinds of things -- what kinds of activities they're conducting. And I won't -- I think you can see these on your slide so I won't go through them in detail.

But the national SIDS and infant death resource center is basically the national repository for resources and information on SIDS and infant death. And it provides a wide variety of professional and consumer education materials. Many of you are familiar with some of its publications. Next slide, please. This is their signature piece, what is SIDS, and this is the hot of the press 2004 version. It highlights the characteristics of SIDS, the risk factors, diagnosis, risk reduction, current research, working with families, and general resources. It's available free in quantities from the resource center and it was recently published in Spanish. And I hope that states are taking advantage of getting quantities of these publications and distributing them to your people. There are a couple of recent publications from the resource center are responding to a Sudden Infant Death Syndrome, the professionals role. SIDS deaths by race and ethnicity. Contact the resource center directly to take advantage of those.

Next slide, please, the resource center provides a list of recent acquisitions and produced bibliographies on a number of topics. These annotated lists and the bibliographies and new publications are announced on Project IMPACT state to state listserv and I'll tell you more about that in a few minutes. The national SIDS and infant death program support center is a partnership between the Maternal and Child Health Bureau to best meet the needs of families and others who are or have the potential to be impacted by infant death. You can see there the various ways in which they do this, education and training, technical assistance and building partnerships. Next slide, please. The national center for cultural competence has a special project that focuses on SIDS and infant death and they provide training technical assistance and consultation to increase the capacity of SIDS

programs to ensure that their services are culturally and linguistically appropriate. Next slide, please. The national SIDS and infant death Project IMPACT is a partnership between the association of SIDS and infant mortality program more commonly known as ASIP and the Maternal and Child Health Bureau to support state and local infant death programs through sharing information, promoting policy and legislative changes, building upon resources and fostering partnerships and communication.

You'll hear more in detail about all of these programs what I've tried to do in this presentation is lay out for you examples of the kinds of initiatives and products that are coming from the centers and hopefully this will help you to figure out what are the best things that support your work at this time. And ways to access them from the four centers. Next slide, please. The Maternal and Child Health Bureau partners with parent and professional members of the SIDS and infant mortality community. I'll say right now I apologize because I cannot name them all here. There is a wide varied range of organizations who are working with the Maternal and Child Health Bureau, with Title V, with Healthy Start. We've mentioned a few of them. The American Academy of pediatrics, the C.J. foundation for SIDS, child death review, national and state programs. The fetal infant mortality reviews and there are many, many more. What I would encourage you to do, if you would like to be mentioned in this particular webcast, is send us in a comment and a question and you'll get mentioned. But please accept my apologies because I can't include everybody here. Next slide, please.

One of the key organizations that does have a direct relationship with the bureau through a cooperative agreement is first candle which is formerly known as the SIDS Alliance. And first candle began as a group of SIDS parents searching for answers and support to deal with the loss of their healthy, normal baby. In 2002 the board of directors decided to change the vision and the mission of the SIDS Alliance to include infant death from the perinatal period up to two years of age. The name change reflects their expanded vision of all babies surviving and thriving to reach their first birthday and beyond. First candle has 51 members throughout the nation as well as numerous strategic corporate partners. They concentrate on research, advocacy, bereavement support and education. As I mentioned, the cooperative agreement between first candle SIDS Alliance and the bureau supports the program support center. Next slide, please. Another of the organizations that the bureau works directly with is ASIP formerly the association of SIDS program professionals. ASIP was formed in 1987 to fill in the gap between the then diminishing federally funded program for SIDS and the thousands of families who needed bereavement support on the loss of a child to SIDS.

It was in 1996 that the organization changed its name to the association of SIDS and infant mortality program to reflect the expansion of services to broader based bereavement support and training. ASIP is a professional membership association for those who provide counseling and support and community education training programs and consultation services on SIDS and infant death to health departments, emergency responders, medical examiners, coroners and law enforcement. ASIP holds an agreement that funds Project IMPACT. Some other organizations in bereavement support who

partner with the four centers and the various organizations we've mentioned include the association of death educators and compassionate friends. Next slide, please. This slide says slow down but really buckle your seat belt. We have a lot to share with you and we don't have it all and we don't pretend to. What I say is don't get mad if you're not in here. Get even better coverage of your program by sending information to Project IMPACT. Our contact information is at the end and I will put it on the state to state listserv read by 500 people and we'll find other ways to promote it.

Please do send your information in to us. I want to take a look now on the next slide at some of the state SIDS and infant death program resources that have been developed in - - as companion pieces to the national back to sleep risk reduction campaign and I'm going to show you several samples of state campaign materials on risk reduction. Most of them take the back to sleep message to the next step and include risk factors of temperature, crib bedding, co-bedding and tummy time. This particular one is from Indiana. And you'll see that it's in both English and Spanish. Throughout this presentation you'll see resources and outreach initiatives for Hispanics. I think this might seem a bit unusual since Hispanic populations are currently experiencing the lowest SIDS rate in the United States. Public healthcare professionals need to not place all Hispanic populations into one group. The data are useful for targeting limited resources and allocated services but each state needs to be sensitive to the need of population and data within their own state rather than national averages. Hispanic populations are also reporting the lowest rates for prematurity, lower birth weight and smoking. They have the most children living in poverty, are the highest rates of high school dropouts, teen pregnancies and underutilization of

pre-natal care. This is a sample of a back to sleep campaign from the State of Georgia. Next slide, please.

This is one from Alabama. Again, this is translated into Spanish. Next slide, please. This is another one from Georgia. It's done in partnership with safe kids. Used to be safe kids are no accident, safe kids injury prevention campaign and several other partners to reach African-Americans. Now some concern has been raised in the field that SIDS and infant death programs not be absorbed into injury prevention for fear of risk reduction might be strengthened by that but bereavement support could be forgotten. It doesn't mean don't partner with them but how you structure the partnership so that it doesn't overshadow the need for bereavement support. Developing public private initiatives and it's something that Project IMPACT is interested in helping state programs look at to they can identify corporate and other public/private initiatives in their own states and localities. Next slide, please. This is a brochure from Florida and you can see that there are so many ways that the same message can be delivered. That's the challenge of public health education. Next slide. This is from the consumer product safety commission on sweet dreams. It's also a back to sleep risk reduction message and this particular one is the State of Virginia's adaptation of the CPSC materials. It is available for states to add their own logo or state contact information.

And so we encourage you to take advantage of these free resources if your program is struggling with limited resources. Next slide, please. One of the challenges as we've just seen is expressly how to deliver the message when we're dealing with health behaviors

that are comprised of several activities and involve more than one person. In this case a parent and a child. An infant and the outcome of which is decided by many confounding factors. There has been an ongoing debate about co-sleeping and bed sharing and how to communicate about it. On the state to state listserv. And you see here the point of view that it's important to simplify the message and leave it to the audience to determine individual considerations. Next slide, please. But here is the opposite point of view that it's incumbent upon healthcare educators to Taylor the message to the audience and one of the values of the listserv is that it enables state programs -- states SIDS and infant death program staff and researchers and other clinicians and advocates and policymakers and so forth to exchange their thoughts about these issues. And I think it helps to further sharpen all of our thinking on how we're going to deliver these very challenging messages. Next slide, please.

But the professional organization, the association of SIDS and infant mortality programs has developed two papers for professionals in the field to address this challenge in the meantime until it's sorted out. One is on breast feeding sudden infant death syndrome and safe sleep environment and the second is on counseling implications and it will give you a summary of the research and some directions on how you may counsel and provide risk reduction messages to the families that you're working with in your communities. Next slide, please. Some states have steered away from co-sleeping and bed sharing issues and focused on the hazards of placing infants in adult beds. This particular poster is from the central Virginia perinatal region and it's also available for states to adapt. It's been quite popular in that geographical area which includes the capital of Virginia, Richmond,

where they're suffering from very serious increases in SIDS deaths and in deaths from where there is co-sleeping in the death scene investigation. Next slide, please. The consumer product safety commission has also put together a very practical piece on crib safety and you can see it there. In the vein of going upriver to see where all the babies were coming from.

A story told at conferences where the babies were being thrown into the river and people were fishing them out and somebody decided to go upriver and they saw somebody throwing the babies into the water and realized they could do a little primary prevention rather than secondary. Several states have started what are called cribs for kids programs where they provide a safe sleep environment by providing a crib to families that can't otherwise afford a crib. Notably Pittsburgh, Pennsylvania and more recently Philadelphia is beginning a program like this. The maternity care coalition and SIDS mid-Atlantic has one as does Washington, D.C. and Indiana. I know there are probably cribs for kids programs west of the Mississippi and I hope that those people will listen in today and let us know where those programs are. Please use that question and answer session at the end of this program so we can be best informed. Next slide, please. Now we want to take a quick look at some of the resources available for professionals in bereavement support. This guide for home interviewers was developed by the national fetal infant mortality review and the association of SIDS and infant mortality programs to help prepare interviewers as they worked with grieving mothers and available on disk. In a few states SIDS and FIMR's, they both face limited resources and this is one way in which they're trying to meet the needs of families on a bereavement support side.

It is complicated by the methodology of FIMR's and the way they differ from SIDS. Often the time of the interview is -- it's a different time frame. But there are some things that are - - some states are working on the integration of home interviews. Next slide, please. This is a policy brief from the national center on cultural competency and provides rationale for having linguistic service to families following the death of an infant. Policy recommendations for the many systems that interact with those families. All of the NCCC publications and products are available on the website and most of them are available in English and Spanish. Next slide, please. These are some resources for parents. The one on the left is after sudden infant death syndrome facing anniversary, holidays and special events available from the resource center. The one on the right is available from first candle SIDS Alliance, both publications have parents learn about the grieving process, about children's reaction to death and include suggestions for friends and relatives on how to help. Next slide, please. The SIDS survival guide is something that's recognized by a lot of people who have worked in this community in the past decade, anyway. And it is written by Joni and Robin Morris.

They've sold 30,000 copies since its first publication in 1997 and just recently became available in Spanish. The SIDS network is a good national resource with the latest information on SIDS and links to the SIDS discussion group for families, researchers and professionals. A lot of parents who aren't in metropolitan areas or not in an area where there is a support group available have turned to the Internet and found great comfort in identifying chat rooms and listservs and discussion groups online where they can access

support -- peer support often at any time of the day. Next slide, please. This is first candle SIDS Alliance's website. This is the version of the website that will be in Spanish and it will be available December 1. So happy holidays. And the next slide shows the national -- the staff of the national SIDS and infant death resource center staff and they are at your service. All of these resources that we've been talking about and more can be gotten through the national SIDS resource center and their director is not pictured but she would be happy to take your calls as well. And Nan can help you with a specific search that you have. Please take advantage of that really great service from the resource center. Next slide, please.

Well, the national SIDS and infant death program at the federal level does have limited resources and faces the same considerations as the states do of where to allocate funds. Just as the states turn to their needs assessment and data the federal government realized that while SIDS rates were declining, the number of infants dying in childcare represented a fifth of the babies dying of SIDS. Based on the work of Rachel moon and others the government worked on reducing the risk for SIDS in childcare. Next slide, please. The Healthy Childcare America back to sleep campaign was launched in January 2003 and it brought together two campaigns, the Healthy Childcare America campaign and the back to sleep campaign and brought together childcare, risk reduction partners across the country to focus on reducing the number of SIDS death in daycare. Here you see the results of Healthy Childcare America focused on setting standards for licensed family daycare homes across the United States. Next slide, please. So the Healthy Childcare America back to sleep campaign includes a number of resources. You can see

on the left that the standards -- there are 10 standards on SIDS that -- this is the second edition of caring for our children which included the ten standards on SIDS.

On the right is a speaker's kit which the national SIDS and infant death support center partnered with the Maternal and Child Health Bureau. And the support center recently created a Spanish version. Both the program support center and the association of SIDS and infant mortality programs continued to conduct childcare provider training and the National Center for cultural competence made sure they were culturally and linguistically appropriate. The American Academy of pediatrics and the bureau are launching a program to evaluate the effectiveness of this campaign looking at four states, and very specifically going into the childcare settings to explore how the behavior of back to sleep is being implemented. Next slide, please. I might say about the AAP bureau campaign that they're looking for states with the highest infant death rates, SIDS related deaths in childcare so if that is your state, be in touch with AAP, Loren would be your contact. The national resource Center for safety and childcare would be the place to go for the grantees from the Healthy Childcare America campaign and also for SIDS state programs because it provides technical support on the issue of legislation and licensing related to childcare. It has the ten standards on SIDS which you can download and duplicate and offers the complete publication on national standards to reduce the risk of SIDS based on caring for our children.

This information is geared toward assisting states in forming licensing requirements to reduce the rates of SIDS and reflects best practices for health and safety in childcare.

North Carolina's SIDS law went into effect last December. Childcare providers who are licensed to care for children 12 months of age or younger must receive the required SIDS training and North Carolina moved on the issue looking into deaths in the childcare setting published in early 2003. Chris OMARA is the director in North Carolina and get in touch with her and she can tell you the political strategies useful in getting this kind of legislation passed. New Jersey's Division of youth and family services has published a manual of requirements for childcare centers and these regulations went into effect in February of this year for a five-year period and also available through a link at NRC's websites. Two examples -- there is a rich amount of resources and you can look up your state or any state to see what progress they've made in licensing and training in childcare to reduce SIDS-related deaths. Next slide, please. In addition to ASIP's paper on infant sleep positioning they've developed materials available for state programs. You see them pictured here. Some of them -- this particular one includes emergency procedures for an unresponsive infant.

This is designed so it can be posted by the provider and encourages providers to practice their response. Next slide, please. Daycare providers, as we all know, are not only found in licensed day-care centers. One of the biggest challenges to reducing SIDS risks in childcare is to reach daycare providers, many of whom are grandparents. 4.5 million grandchildren live in grandparent-headed homes often without a parent being present. I think that's a pretty impressive number, 4.5 million. Project IMPACT partnered with AARP to put risk reduction guidelines in the grandparent information center, a quarterly newsletter that goes to 40,000 grandparents across the country. You can see it in this

year's fall edition. For those of you who aren't reading the grandparent information center voice, the program support center has developed materials for grandparents that are available to the states. While we know that the AARP's demographic is not necessarily the target audience that we want to reach as far as childcare, the thinking by Project IMPACT and others is that it's a way for us to amplify the message and ensure that the same message is coming from many sources so that we hope that this message of back to sleep and the relevant risk factors is being institutionalized throughout all populations in the United States. Next slide, please.

The association of SIDS and infant mortality programs laid a foundation in 1996 for childcare training with their train the trainer program for infant care providers and professionals who were interacting with families who have lost a child. The bureau had identified this problem a few years earlier in 1994. They did a nationwide needs assessment of SIDS services and found that they needed to have training for the group of professionals in many disciplines who were responding to families who had lost a child. And ASIP came up with that training. More recently, the program support center has completed this train the trainer manual which focuses solely on childcare providers and is available, you can again contact the program support center or the resource center to get a copy of it. It's a very comprehensive manual and includes Power Point presentations that are downloadable and I think you would find it a very valuable resource if you are launching any kind of initiatives to reach into childcare. Next slide, please. Where else is the federal government focusing its resources? We've seen this great drop to 2,300 deaths in 2002. I think it's one of Dr. Duane Alexander's favorite bedtime stories. An

amazing public health story. Even with this dramatic decrease in the incidence of SIDS, African-Americans and Native Americans are at higher risk than white infants.

What the federal government is doing is targeting the risk reduction outreach and studying what works with specific audiences. Testing it, bringing the audiences in to help develop messages and so forth. And now we're going to look at some examples of that. Next slide, please. All four of the national SIDS and infant death programs support targeted outreach. In addition to special populations and those we've already mentioned, parents, childcare providers, audiences include health professionals and educators, state SIDS and infant death program professionals, first responders and death scene investigators, legal professionals, medical examiners, researchers and policymakers. Let's look at some of the examples of outreach. Next slide, please. The program support center is partnering with the NICHD on risk reduction continuing education for nurses and targeting states with large disparities. So you can see that they worked with Mississippi. They're very focused on helping to get the message to African-American audiences. Next slide, please. The resource center has developed sudden unexpected infant death information for the emergency medical technician. This is a new publication just out in the past couple of months. The state EMS offices have been quite responsive.

They appreciate having a fact sheet to provide an overview of the EMT's role in responding to Sudden Infant Death Syndrome and grief responses, causes of SIDS and the difference between SIDS and child abuse. Important consideration especially with our changes in understanding more about co-sleeping. We need to sort out child abuse

deaths from that. So the death scene investigation becomes very important. I would like to encourage you at this point to think of any questions that you have. I know that this has been a really a presentation of resource -- resources from the resource centers and the various projects. But if you don't have questions, please consider adding your information on resources to this list and send it in to us during that period. The program support center developed these guidelines to use for a variety of professionals and they're available to states. The New York State Center for sudden infant death has a New York City satellite office led by Evelyn they developed a risk reduction education that combined three target audiences, African-Americans, grandparents and worked through the churches to reach grandparents and elders to reduce the infant mortality disparity. This is a really nice piece of lessons learned. I encourage you to take a look at it. Next slide, please.

This is a useful publication for planning outreach. NCCC's guide to choosing and adapting culturally and linguistically competent materials. They are in the process of releasing a new training video and they realize that travel for state and local programs was very difficult now so they had to rethink how they could provide the training. What they did is taped this training video to be used by individuals or groups locally and when it's ready, which is going to be shortly, we will put it both on the state to state listserv and it will also be on the NCCC website. Next slide. The NCCC has some limited resources to provide direct consultation and training for SIDS and infant death programs but they can't reach all the programs. And what they've done is put together a consultant pool on their website with expertise in various aspects of cultural and linguistic competence. Go to the consultant pool page and look for the consultants. All of them in the pool have had

reference checks by the NCCC staff. If you find someone who looks promising you can contact NCCC and they'll put you in contact with the consultant. Unfortunately they will not pay for the consultations, they're just brokering them for you. Next slide, please.

The national resource center represents all of the bureau sudden infant death and infant death programs when it exhibits six times a year and often more than that. The resource center places the exhibits each year at the beginning of their contract year but welcome your suggestions for conferences and audiences. That's another thing you might consider sending in right now as you're listening is what are the audiences that you think we need to be reaching, either at the state level or nationally. What professionals, what kinds of healthcare providers do we need to be getting to with the risk reduction message or with the details of providing bereavement support? Next slide. This is a new partnership, Project IMPACT worked for the association of clinicians for the underserved to get the message about back sleeping out to a different group of providers. ACU is individual clinicians and community migrant, homeless and academic healthcare systems. When Project IMPACT partnered with them earlier this year to get the calendars out by January when they would be useful. 10,000 of these calendars were distributed to healthcare providers and policymakers around the country and hopefully those of you listening, if you're healthy start directors or Title V directors also received the calendars. We hope you enjoyed them. Next slide, please.

This year the ACU and Project IMPACT are partnering to develop a clinical tool. This is something that the members of ACU used. It's a laminated card on a ring and this

particular one that the photo is of is on oral healthcare. We're going to develop one with ACU on healthy pre-natal care behaviors and risk reduction messages. The idea of it is that the provider can put it in his or her pocket and take it out for a quick reference. I was a little skeptical but ACU has tested these and found that their members really do appreciate them. So we thought it would be a very important audience to reach and we want to help clinicians respond to the occasional loss of an infant. They may not get it in their practice a lot but we would like to provide information on appropriate responses to parents' varied expressions of grief. The death scene investigation, what are the responsibilities of medical personnel, bereavement counseling resources for their patients and support for their own response to a loss. So those are the things that will be included on this tool. Next slide. The Project IMPACT and others have been exploring partnerships with anti-tobacco organizations. It's a good way to leverage limited resources. This particular slide is looking at an example of using SIDS information to reinforce a campaign against second hand smoke.

And the national partnership to help pregnant smokers quit is another national group that has many resources available for state SIDS and infant death programs that are focusing on smoking as a risk reduction factor for SIDS. They've developed a lot of materials for American Indian audiences that have been used very successfully and we encourage you to continue to work with that program. Next slide, please. This is an example of some of the things that state partnerships are doing to strengthen outreach to target audiences. The grief assistance program, which is the state SIDS program in Pennsylvania partnered with the national coalition of 100 black women and the C.J. foundation and mercy hospital

to reach out to African-American audiences with the risk reduction message. Next slide, please. Now, in 2003 the association of SIDS and infant mortality programs and NICHD met together with representatives of the American Indian communities of the northwest, northern plains and Alaska Natives to identify community action driven plans that could reduce risk for SIDS and preserve cultural traditions. The recommendations for the meeting are available in this report. There have been a number of follow-up meetings and focus groups have been conducted and plans are to develop new outreach strategies based on the findings.

You'll be hearing more about that soon from NICHD and ASIP. And another way in which we partner with the Indian Health Service to reach American Indian Alaska communities, the child health coordinators are participants on the state to state listserv. The C.J. foundation worked with the Indian Health Service and the Office of minority health to develop a multimedia training kit designed specifically for American Indian, Alaska Natives. Two videos on risk reduction, and the great lakes intertribal council and a number of other training materials. They put together 4,000 kits and more than half of them have already been distributed. These are available free for those states who would like to conduct outreach to American Indian communities. Next slide, please. In the 1990's, the bureau recognizing the value of service to all families who are experiencing an infant loss from any cause began to shift its emphasis from Sid-specific services to a broader model which combined other deaths as well. They explored the methods and the state and local coordination efforts. The next slide.

Then at the request of the Maternal and Child Health Bureau in 2000, the association of SIDS and infant mortality perhaps ASIP convened a meeting for state programs to try to define further other infant deaths and to develop recommendations for a framework to guide local programs who were expanding their services. Next slide, please. And most recently, three states who have expanded their services to include other infant deaths, Wisconsin, Massachusetts and Utah, were interviewed and the lessons learned from those interviews are in this publication which is available from the resource center, the HRSA clearinghouse. Take a look at that. Next slide, please. As SIDS numbers decreased and programs wanted to expand to other infant deaths, the bureau wanted to understand the role that a diagnostic shift that the coroners might be playing. It looked at the variation of SIDS diagnostic proper--procedures. It looks at a small sample of states and the differences in the way the death scene investigation was being conducted. Next slide, please. CDC has followed this up and convened an advisory committee to develop a form for death scene investigations that we hope will make death scene investigations around the country uniform or more uniform and the program support center and ASIP and others served on this advisory committee.

The comment period for the very comprehensive form that they just developed, that the committee developed, just ended last week on November 12. The form will now be sent to medical examiners and coroners with training to follow that will be conducted by the national SIDS and infant death program support center. Next slide, please. The national SIDS and infant death projects impacts state to state listserv I've mentioned several times in this presentation and I would like to encourage any of you who are not members,

please join us by looking at the contact information at the end of this presentation. We have 480 members on the listserv and it's very active. It's been in existence for just over a year. And it really provides an exchange for researchers and practitioners that we don't think can be found anywhere else. Its informal conversations about some of the topical issues of the day that are of concern people running programs and doing research. You can see here some of the things that have been covered on the listserv. I put this together in fun. The topics A to Z. In truth, the -- it's amazing what topics we do cover on the listserv and so I encourage you to join us and if you would like to look at past postings those are available to you as well. Next slide, please.

These are just some examples of some of the kinds of things that have come up on the listserv and that turned out to be resources for people who are conducting programs at the state level. This is a nursery protocol that was developed by Jennifer in Virginia for a neonatal intensive care nurseries. There were problems with -- with preemies being placed on their stomachs to sleep because of respiratory considerations and some parents were going home with them. Because they had seen that behavior modeled, by putting their infants on their tummies and this is a protocol that ensures that nurses are helping to teach parents before they go home with their preemies or with any other babies that were in the unit that they should -- what is the best, safest sleep environment for their babies. Next slide, please. These are -- this is a brief from the national governor's association, one of the partners of Project IMPACT. And it's on efforts to improve birth outcomes and reduce high-risk births. This is just another example of what we try to bring you easily accessed through the listserv. Next slide, please. This is a guide to core

competencies for any healthcare professional dealing with bereavement. It was developed by the association of SIDS and infant mortality programs.

It's comprehensive and I think should be on the desk of all of the state and -- state SIDS and infant death programs because it enables you to look at what services in bereavement support and risk reduction counseling and understanding grieving processes and so forth. What are the standards that professionals need to do in order to provide the most comprehensive services for their families. Next slide. Also for the -- for all of the state programs forth coming is a program development manual for those who would be starting a SIDS and infant death program or who want to look at how to build their program that is already in existence. And you can see that this is coming out from the program support center in January, this coming January, and it will provide information on how to set up and run a SIDS and infant death program. Next slide, please. And this is a final slide on the National Center for cultural competence just to remind you that you can go to their website. These are -- these resources, the state to state listserv, the core competencies manual and the manual on developing programs and finally the National Center for cultural competence website I think are four tools that we would like to encourage you to use over and over to strengthen your programs at the state level.

Finally, there are signs which tell you how to contact the four centers. You can look at those at your leisure and now I would like to just encourage you to work together with us to learn more about the centers, contact any of us. And I wish you good luck in continuing

to serve the families and work with other providers to reduce SIDS and infant death.  
Thank you.

PAUL RUSINKO: Thank you, Lori. I know this is a very intense presentation. We had a lot of information to try to share with you. And we -- I would like Lori to give the phone number of the Project IMPACT office in case people would like to follow up on any of the individual numbers. Do you have an 800 number?

LORI COOPER: 800-930-7437.

PAUL RUSINKO: At this time I don't believe we have any questions. I would like to encourage either people taking some time out now to submit some questions or as Lori had said earlier, to share some of the resources and program activities that you're doing that actually present lessons to share or models to share with other programs.

LORI COOPER: I would encourage you even the write in and let us know what are the challenges that you're facing. This was a lot of information and material. We are just -- we're excited about so many things that are going on in the community and we want to try to bring you all of the support that we can. But if there are partnerships that are different or unusual that you're in, please let us know about that. If you are facing hard questions about co-sleeping and bed sharing, you know, this is a good time to help us identify some

of the issues we should be pursuing to bring information and support to you as you conduct your program.

PAUL RUSINKO: We have a question here from Chris in North Carolina, the North Carolina Healthy Start foundation has just launched an outreach to hospitals to promote infant safe sleep policies. It would be helpful to learn what others are trying to do for hospitals in education. How can we attain a copy of the sleep position protocol for the NICU that was developed in Virginia?

LORI COOPER: Thanks, Chris. I would be happy to send that to you. Your wish is our command. Along those lines, it would be interesting to learn if any of the state programs either have developed or are aware of in-house hospital videos. This is a way that hospitals use to educate new mothers quite frequently on breastfeeding, giving the baby a bath, all kinds of parenting behaviors and activities. And it would be very useful to know if there are any tapes available that focus on safe sleep positioning, environment and risk reduction. At Project IMPACT we haven't heard of a lot of those. We haven't heard of a lot of those that are very interested in whether that is becoming institutionalized in hospitals that have that in-house cable capacity.

PAUL RUSINKO: We have a question here, Suzanne has a request. How can a program obtain brochures and materials for families in large quantities?

LORI COOPER: I would suggest that you contact the resource center and I don't know their number. They also have an 800 number. I don't know it offhand but it is at the end of the slide presentation, there is a contact there. The what is SIDS publication that the government just printed 50,000 copies of it. So please have at it. We would like to get them out and we don't want to see any. The resource center doesn't want them on their shelves.

PAUL RUSINKO: The California program has a wealth of materials on SIDS, grief, bereavement. For more information please call the program at 916-266-7437 or access our website at [www.CaliforniaSIDS.com](http://www.CaliforniaSIDS.com). Thank you.

LORI COOPER: I want to say that California has exquisite materials and we would like to encourage anyone who is working in these programs to just go to their website and look at their materials. They are -- they're attractive and they also have them in such a wide range of languages that I think you'll find them very helpful in that regard.

PAUL RUSINKO: Thanks.

PAUL RUSINKO: With that I would like to thank everyone for joining us on the webcast today. And certainly as Lori has said, let this be the beginning of a continuation of communication with you. Please get in touch with Lori or the other resource centers that can provide services to help improve your programs' operations; I thank you for joining us today.