THE SECRETARY'S ADVISORY COMMITTEE ON

INFANT AND MATERNAL MORTALITY

UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

VIRTUAL MEETING

Day 1, June 15, 2022

11:00 a.m. - 5:00 p.m.

COMMITTEE MEMBERS

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Tara Sander Lee, Ph.D., Senior Fellow and Director of Life Sciences, Charlotte Lozier Institute

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M. Kathryn Menard, M.D., M.P.H., Upjohn Distinguished Professor, Department of Obstetrics and Gynecology, Division of Maternal-Fetal Medicine, University of North Carolina School of Medicine

Joy M. Neyhart, DO, F.A.A.P., Rainforest Pediatric Care, Member, Southeast Alaska Regional Health Consortium

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ShaRhonda Thompson, Consumer/Community Member

Jacob C. Warren, Ph.D., M.B.A., CRA, Associate Dean for Diversity, Equity, and Inclusion, Rufus C. Harris Endowed Chair in Rural Health and Health Disparities, Director, Center for Rural Health and Health Disparities, Director, Rural Health Sciences Professor of Community Medicine, Mercer University School of Medicine

Paul H. Wise, M.D., M.P.H., Richard E. Behrman Professor of Pediatrics, Health Policy and Society, Stanford University

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C O N T E N T S

P R O C E E D I N G S

WELCOME AND CALL TO ORDER

LEE WILSON: Good morning, folks. My name is Lee Wilson, and I am the Director of the Division of Healthy Start and Perinatal Services in the Maternal and Child Health Bureau at the Health Resources and Services Administration. I'm acting as the designated federal official for opening the Advisory Committee on Infant and Maternal Mortality, the June meeting, which is being held Tuesday, June 14 and Wednesday, June 15. This is a public meeting. All are welcome. And our advisory committee is convening today to discuss the issues that have been presented and outlined in the Federal Register notice.

Just before we begin the meeting, I'd like to make a couple announcements. First, welcome back to Vanessa Lee, the designated federal official who is returning after parental leave. She will return into her official role as designated federal official following this

meeting, but she is here for moral support, good input, and wisdom, and we appreciate her return. She's also brought with her a new junior employee named Iris, and we look forward to working with baby Iris as well.

Second, I'd like to thank Anne Leitch on our staff at the Maternal and Child Health Bureau, who has been working to support the advisory committee in Vanessa's absence, and has done a fantastic job of stepping in, learning the ropes and being just the epitome of support in the development of our agendas, working with Doctor Ehlinger on the committee and making sure that all of these meetings run smoothly and well. Also, thanks to Abigail Duchatelier who is the core for the logistics contractor and the work that she's done in preparing the minutes for approval.

I do want to announce that we have extended committee members who would be expiring in June following this meeting to give them the opportunity to participate in the September meeting since we have juggled our meetings around.

So, for those of you who had requested an extension, those extensions have been approved, and I believe you've been contacted by our ethics officials and by Anne Leitch.

I also want to acknowledge Jeanne Conry and Paul Wise, who are rolling off the committee after this meeting. I'm not sure that either of them are going to be able to participate in this meeting, but they had committed themselves to many years working on the committee, and provided just a wealth of expertise, insight, and wisdom in guiding the direction of the committee on the topics that they've invested themselves in. So, thank you officially to them.

And, finally, I'd just like to welcome all of you to this meeting. And we look forward to your participation and insights on these issues. So let me turn it over now to Ed Ehlinger, the chair.

CHAIRMAN EHLINGER: Thank you, Lee. Let me welcome all of you. Good morning to everyone. And I know that our country is

experiencing rain and fires and heat, and I hope all of you are safe where you are. And so, I'm glad you're with us.

I want to also add my thanks to Anne for all of the work that she's done over the last several months in Vanessa's absence. We really appreciate it, and all of the people at MCHB that has made all of this possible. So, all of those people that you mentioned, Lee, I've not worked directly with some of them, but I know indirectly I have worked with all of them. And I really appreciated working with Anne. It's been really, really nice.

So, can we just kind of go on gallery view and take off the slide?

So, I want to first acknowledge that here I am. I'm Ed Ehlinger, and I'm in Minnesota, the ancestral land of the Dakota and Ojibwe. It's actually an important day here. I don't know about an important day, but it's a celebratory day because just yesterday Owamni, a restaurant in Minneapolis that serves only Indigenous foods --

it's run by Sean Sherman, who calls himself the Sioux chef, S-I-O-U-X chef. He won as the best new restaurant in the James Beard Award nationally. And so, I'm thinking that when you all come to Minnesota in September, we probably have to make reservations now to that restaurant, because I know already, they're three months booked out. So, I think it's really nice that we're acknowledging all of the Indigenous folks and the Indigenous foods here in Minnesota and nationally recognized with the James Beard Award.

So, with that, you know, I sent to all of the SACIMM members, the appointed SACIMM members an instruction last night about how to introduce themselves, and I'll give you a little background. There's a planning method called backcasting. I don't know if you know about it, but it starts with defining a desirable future, and then works backwards to identify the policies and programs that will connect with each other, that connect the future with the present. And the final or the fundamental question with backcasting

is, if you want to attain a certain goal, what actions must be taken to get there. And so that's what I've asked the SACIMM members to do with their introductions. Along with their name and title and position, I want them to answer this question, what will it take to, and then they get to fill in the blank of whatever the public health goal and objective is. And it can be expansive or narrow. It can be objective or subjective, visionary, or very practical. And they get to do that in less than a minute. Normal backcasting sometimes takes months to do. We're going to do it in a minute.

INTRODUCTIONS

CHAIRMAN EHLINGER: So, I'll start out. I'm Ed Ehlinger. I'm the former Director of Maternal and Child Health with the Minneapolis Health Department and former Commissioner of Health in Minnesota. So, my question is, what will it take for SACIMM to develop a set of powerful, strategic, and impactful recommendations related to the health of First Nations and

Indigenous mothers and infants. It will take the involvement, commitment, and prioritization of time of every member of this committee. So, with that, that's my introduction. And I will now kind of go down alphabetically.

So, Sherri, Sherri Alderman?

SHERRI ALDERMAN: Hello. Thank you very much. My name is Sherri Alderman. I am located in Portland, Oregon. What will it take to address the unacceptable disparities in health and wellbeing of children? And what it will take is for us as a society to realize the rights of children, the rights of children for all children in our country and around the world.

CHAIRMAN EHLINGER: Thank you. Steve Calvin?

STEVE CALVIN: Hi, Steve Calvin, Minneapolis, Minnesota. I'm not too far from where Ed is. I'm a maternal fetal medicine specialist who works with midwives at the Minnesota Birth Center. What would it take for kind of a more coherent and responsive maternity

and newborn care system? And I'm hoping that the work with SACIMM, which some of it's already been started, and some is, I think, pending in the future, how we can develop team-based care models that include physicians, midwives, doulas, community health workers, nurses and all those concerned to provide care in a way that meets the needs of both the urban population and the rural population.

CHAIRMAN EHLINGER: All right. Thank you. Next on my list is Charlene Collier. I know she's coming. She might be getting here a little bit late. She's coming from another meeting. And Jeanne Conry, as Lee said, is not on the committee anymore or is going off. Tara Sandra Lee cannot make it today, but she will be here tomorrow. And Colleen Malloy will be in and out through most of today, so I don't think Colleen is on right now. I don't see her name.

So, then Katheryn Menard, Kate Menard.

KATE MENARD: Good morning, everybody. What will it take, what will it take to ensure

that every pregnant and postpartum patient, person can access high quality, holistic and well-coordinated care that's appropriate and tailored to her medical, cultural needs and preferences? What that would look like would be that every individual that has uncomplicated pregnancies can receive comprehensive quality care delivered in and by their community, those at high risk for complications due to medical and obstetric conditions receive well-coordinated multidisciplinary care that they deserve in a location or facility that's prepared to meet their needs and those of the babies. What we need to do to accomplish that is have our clinical colleagues, our public health colleagues, and our policymakers, including payers, work in collaboration toward that end.

CHAIRMAN EHLINGER: Great. Thank you, Kate. Joy, Joy Neyhart.

JOY NEYHART: Good morning. I am a primary care pediatrician working with the Southeast Alaska Regional Health Consortium, which

is a tribal health organization in southeast Alaska. I was recently employed by them, and I'm working with them as a primary care pediatrician, and also helping to develop their new service line, which is primary care pediatrics. Previously they were just a family health dominated, or a family health organization.

In any case, my question is what will it take to reduce poor outcomes for all families, and poor outcomes, including mortality, school failures, substance misuse, poverty, incarceration, domestic violence and SUID can be reduced by using the evidence we already have to appropriate funding for services for pregnant people and early childhood. We know that for every dollar spent six to 10 are saved. And so, if we could do that, we would improve lives for all kids and all families. Thank you.

CHAIRMAN EHLINGER: Thanks, Joy.

Janelle Palacios?

JANELLE PALACIOS: Hi. I'm speaking to you from ancestral Pomo and Miwok lands in

Northern California. And I just want to say that I love how Ed stated we could give something practical or visionary, so I'm going to give you something visionary. I'm Janelle Palacios. I am Salish and Kootenaie. I am from the Flathead Indian Reservation in northwestern Montana. I currently live in Northern California, and I practice as a nurse, midwife, researcher, and consultant. What will it take to improve the health and wellbeing of all people in our nation? It will take us seeing each other not as other, but as neighbors, as family, as friends, as humans. I believe a good step forward meeting this goal is to start with history, and for our nation to address its history to promote healing, understanding that will, in fact, change policies and general kindness to all fellow humans.

CHAIRMAN EHLINGER: Excellent. Magda, I don't see Magda's name on the list, so maybe she's not signed in yet. And Belinda I know is going to be a little bit late today. Marie-Elizabeth Ramas, is Marie on? I don't see her

name. And Phyllis is not going to be with us. She's in Michigan doing some other speaking. ShaRhonda, I don't see ShaRhonda's name. Jacob, Jacob Warren?

JACOB WARREN: Hey, everybody. My name is Jacob Warren. I'm a health equity epidemiologist, and for the next two weeks I'm the Endowed Chair and Director of the Center for Rural Health and Health Disparities in Mercy University School of Medicine. But as of June 30, I will be the Dean of the College of Health Sciences at the University of Wyoming, thus the new background. So, I actually apologize in advance. I'll be in and out of the meeting over the next couple days, because there's a lot going on at the moment getting ready to go from Georgia to Wyoming in two weeks.

So, my question was what will it take to make sure that all people can receive quality accessible prenatal care. I'm going to take a page out of Janelle's book and hopefully take it up a step to be a little more visionary, because I

think it's a pretty big question. But, to me, I think the answer there is really having to find ways to work across all ideologies and all perspectives to find our common thread of humanity in recognizing that access to prenatal care is a human right. And I think once we start to frame it that way, we can hopefully start to find some paths forward.

CHAIRMAN EHLINGER: Thank you, Jacob.

And I hope you can stick around as much as you can. And Paul Wise, again, will be in and out of the meeting. He has been called down to McAllen, Texas to do some work there, but he texted me last night saying he's really interested in the agenda that we have because a lot of it relates also to what's happening on the border. So, he will be in and out.

Are there any appointed SACIMM members that are here that I didn't call on? Oh, I see now Doctor Peck is now on. So, Magda, if you could, introduce yourself and answer the question that I posed last night.

MAGDA PECK: Try again. Is my audio clear? I'm having a little technical difficulties. When you do work from anywhere in the country, sometimes you have to adapt. So, thank you, colleagues. My apologies for being late today. And allow me to give you my introduction in just a second, which is prepared.

Well, first of all, thank you. My name is Magda Peck. I've served on SACIMM for the duration of this cohort. I serve currently as the Founder and Principal for MP3 Health, which is a consulting firm focused on maternal and child health and equity and storytelling for social change. I also serve as Adjunct Professor of Pediatrics and Public Health at the University of Nebraska Medical Center, where I also am Founder and Senior Advisor of City Match.

So, what will it take -- in a minute, what will it take for research and data, local and state, national and tribal, to be more visible and valued, timely and trusted, available, and used to prevent mothers and babies from death and

disability and eliminate persistent inequities; three things. First, increased investments in the people and practices, systems and structures for more robust data and research methods and innovative technologies that will augment our shared knowledge and understanding and assure that everyone counts and is counted. Second, strategic storytelling to shape and drive more powerful narratives based on the sound science and lived experience that will change hearts and minds and compel social change. And, last, the kind of collaborative, courageous leadership that will give us the wisdom to make difficult decisions together based on incomplete and sometimes imperfect information. That's what it will take to be able to have research and data local, state, national and tribal be the tool we need to be able to drive change for justice and health. Thanks for the invitation. And, again, my apologies for joining you late today.

CHAIRMAN EHLINGER: Thank you, Magda. Anybody else appointed members that I didn’t, see?

I think we got everybody. And just for the members who have been recently appointed, when you look at the minutes of this meeting, you will have all of these things that we can backcast from. These are things that you may be wanting to work on in your four years on SACIMM. So, this is a little template for you to work over the next several years.

Let's now go to some of the other folks on our call. Doctor Warren, Michael Warren, could you introduce yourself?

JACOB WARREN: Thank you, Doctor Ehlinger, and committee members. Good morning. Michael Warren, I'm the Associate Administrator for the Maternal and Child Health Bureau at HRSA.

The question I have is what it will take to get to infant health equity by 2030. As you all know, we have never achieved the Healthy People goals for black and brown babies in this country, and the disparities persist. We know the number. It's 3,700 deaths that we need to prevent every year to be able to get to equity, and I

think we can do it by 2030. But what that will take is a focused effort in communities where the excess deaths are the highest. It will take a commitment to do things differently, because what we're doing now has not closed that gap. And it will take an aligned effort to address those underlying social and structural determinants of health. We have to bake that into our funding programs. We have to require that of our grantees. And we have to work with our partners to achieve that. Thank you.

CHAIRMAN EHLINGER: Thank you, Michael. Anne Leitch, you don't have to give us your backcasting, but you can at least introduce yourself.

ANNE LEITCH: There we go. Thank you. I was having a hard time clicking. I'm not going to backcast because I did not prepare anything, but I just wanted to say that I'm a management analyst who's been supporting the committee in Vanessa's absence while she was on maternity leave. I absolutely love the work of this

committee. I find it fascinating, the perspectives that everyone brings to the conversation, and I've also really, truly appreciated the opportunity to get to know the committee's work better, and work more closely with Ed as well as some of the members. So, thank you.

CHAIRMAN EHLINGER: Thank you, Anne. And Vanessa, do you want to introduce yourself?

VANESSA LEE: Sure, it's hard to follow all of you, but thank you. As Anne and Lee and others have said, I'm just returning from maternity leave as of last Monday, so still generating my brain cells back. But good morning. Good afternoon. I'm Vanessa Lee. I'm the designated federal official for this committee, and I work in the Division of Healthy Start and Perinatal Services at MCHB, and just so happy to be here with all of you again and to meet some of the new members. I just wanted to thank Anne, Abigail, Lee, and Ed for keeping the train running as I was out. And I looked back at the notes. It

looks like you guys had a great meeting in March, and I'm just, again, happy to be back and with you all for this June meeting. So, thank you. Nice to see you all.

CHAIRMAN EHLINGER: Glad you're back, Vanessa. Let's go through the ex-officios to briefly introduce themselves. Charlan Kroelinger?

CHARLAN KROELINGER: Hey, good morning. Good afternoon, everyone. I'm Charlan Kroelinger. I'm the Chief of the Maternal and Infant Health Branch located in the Division of Reproductive Health at the Centers for Disease Control and Prevention. I'm happy to be here.

CHAIRMAN EHLINGER: Good. Cheryl Broussard?

CHERYL BROUSSARD: Hi, everyone. This is Cheryl Broussard. I'm the Associate Director for Science in CDC's Division of Birth Defects and Infant Disorders. Welcome to all the newer committee members. I have served on this committee in the past, and today just filling in for Amanda Cohn and Karen Remley, who had other

committee commitments today. Thank you.

CHAIRMAN EHLINGER: Danielle Ely?

DANIELLE ELY: I'm Danielle Ely. I am the Manager of the Linked Birth and Infant Death File at the National Center for Health Statistics. I'm glad to be able to attend another one of these meetings, and I am looking forward to seeing what happens over the next two days. Thanks.

CHAIRMAN EHLINGER: Good. Glad you're here. Elizabeth Carr?

ELIZABETH CARR: Good morning, everyone. My name is Elizabeth Carr. I'm the Senior Advisor to the Director here at the Indian Health Service and honored to be with all of you today and throughout tomorrow as well. Thank you.

CHAIRMAN EHLINGER: Let's see. Kristen Zycherman?

KRISTEN ZYCHERMAN: Hi. I'm Kristen Zycherman. I'm the Lead on the Maternal and Infant Health Initiative in the Division of Quality Health Outcomes at the Centers for Medicaid and CHIP Services.

CHAIRMAN EHLINGER: Any other ex-officio members that are on that I didn't see?

All right. And then I think there are other people who will be introduced as we go along. Some of them will be presenters, so we will introduce them as they come along. So welcome to everybody. Thank you for being here. We've got a powerful group. We will have more people in and out over the course of these two days, but we will take advantage of every second that you're here.

REVIEW AND APPROVE MINUTES

CHAIRMAN EHLINGER: So, with that, let's move to our first item of work, and that's to review and approve the minutes. Do I have a motion to approve the minutes of our last meeting?

Joy moved and seconded.

I've been sort of listening to the hearings, the January 6 hearing, with unanimous consent, I approve the minutes. I don't know how that all works, but I think it's if you don't speak up, they're approved. So, unless I hear

something in the next couple of seconds, I will take that as unanimous consent to approve the minutes and move on.

(No audible response.)

CHAIRMAN EHLINGER: Good. Yeah. And really, I love the minutes here because they have all of the links to things. It really is comprehensive. If you want more information, those minutes will get you to wherever you need to be. So, thank you for all of that.

SETTING THE MEETING CONTEXT

And then so let us now move forward. Let me give you a little context for our meeting today. You know, one year ago at our June meeting, we finalized the set of recommendations that we submitted to Secretary Becerra on August 4, 2021. In that package of recommendations, we encouraged the Secretary to review the recommendations that we had made a year earlier related to COVID, because many of them were and even still are relevant to today. And we asked

him to consider a new set of recommendations related to five different areas, care systems and financing of care, workforce, environmental conditions related to maternal and infant health, migrant and border health and data and research for action.

And for the more newly appointed members, it should be pointed out that at least two of those content areas really were because of the advocacy of two of our members. You know, they had particular passion, and were willing to take the work and really move the environmental health conditions. Jeanne Conry moved that; and migrant and border health, Paul Wise really moved that. So, there is an opportunity. If you want to take the time and the effort, you can really move an agenda that actually can get some recommendations to the Secretary of Health and Human Services. So that's just as a little aside.

But among all of the recommendations that we had, there was one, quote, "To adequately fund Indian Health Service efforts to reduce

infant and maternal mortality and morbidity," end quote. That was our recommendations. And in our discussion of that topic, we realized that the issue of health of First Nations and Indigenous mothers and infants was much bigger and more complicated than what we could do in that one meeting, and that just the level of funding for the Indian Health Service was not the total issue of what really needed to happen. We needed to have a more comprehensive view. So, we committed ourselves to a year-long examination of the issues facing Indigenous mothers and infants. And now, while everyone acknowledges that American Indians and Alaskan Natives experienced some of the worst birth outcomes in the country, some have questioned the wisdom of focusing so much attention on one population group. You know, an obvious answer to that is that this group, because of its relatively small size, it often gets overlooked and deserves more attention, like any group. But I think the more strategic answer to that question goes actually back to the 1912

establishment of the Children's Bureau, which is the forerunner of today's Maternal and Child Health Bureau, and that 1912 vision of its first chief, Julia Lathrop. And she articulated that vision this way, quote, "The greatest service to the health and education of all children has been gained through efforts to aid those who are handicapped. Thus, all service to the handicapped children of the community also serves to aid in laying the foundations for the best service to all of the children of the Commonwealth." Now, let me explain that, because it can be taken out of context because most people think about handicaps or disabilities in terms of individuals and individual characteristics, for example, children with special health needs. And most people usually think of handicap as just an adjective, a handicapped individual, someone who is restricted by some condition or characteristic that puts limits on that person's ability to function in society. But handicapped is also a population characteristic, and it can be used as an

adjective, as a noun or a verb. With a population focus, handicap doesn't describe the characteristics of an individual, but the impact of the actions of our society on a population. And I think it is this population focused view of handicapped that I think was the real power behind Julia Lathrop's statement. With that population focus in mind, think of these definitions that come from the dictionary. Handicapped, an adjective, being limited or disadvantaged by external forces in achieving optimal development and success; being a part of a system that markedly restricts one's or a group's ability to function physically, mentally, or socially. Handicap as a noun, circumstances that make doing something more difficult, a form of physical, mental, or societal impediment in place that makes progress or success difficult; in a race or competition, a disadvantage of some sort given to someone to make their chances of winning more difficult; and handicap as a transitive verb, implementing a policy or procedure to put someone

or group at a disadvantage.

Now, for too long, we have looked only at the problems of Indigenous individuals, and we have focused and used a disease or deficit focus, which places the onus of the problems on the individual and the solutions to those problems only on their actions. I believe that we should look at First Nations not only as a group of individuals certainly suffering from some of the individual handicaps, but mostly as a population systematically held back by policies, structures, systems, and stereotypes fostered and sustained by our broader society. So, with that perspective in mind, listen again to Julia Lathrop's statement. "The greatest service to the health and education of all children has been gained through efforts to aid those who were handicapped. Thus, all service to the handicapped children of the community also serves to aid in the laying of the foundations for the best services to all the children of the Commonwealth."

So, I believe that our policy and

system development work over the next two days and in September will lay the foundation for the best service to the mothers and infants not just to the First Nations communities, but to all of the mothers and infants of our Commonwealth. That is our charge.

So, over the last year, we focused on a myriad of issues facing First Nations and Indigenous communities, but over the next two days we will be briefed on four additional issues particularly that we have not really focused on, and that is the role of the Indian Health Service, SIDS and SUID, incarceration of pregnant Indigenous individuals and murdered and missing Indigenous women and girls. In addition -- you know, so we'll be briefed on that. In addition, we will examine the draft recommendations that were sent out to everybody that have been developed over the last year, and we will work to clarify, refine, and improve those recommendations. And that effort will continue during the summer with the goal of having a draft

ready for our September meeting. So, this is a step towards that September meeting, which I hope will be here in Minnesota.

Now, in the process of developing this current draft, we have consulted with groups serving First Nation communities, and been guided by the written reports and articles by Native authors and researchers. But personally, I feel uncomfortable submitting whatever recommendations we come up with without really vetting them with the people affected. That's why our September meeting will be held on tribal land and provide an opportunity for First Nations and Indigenous individuals and organizations to comment on our recommendations and on the issues facing mothers and babies in their communities before we finalize our recommendations.

So, in our work so far, it has been really obvious that the issues facing First Nations and Indigenous people are complex and seemingly intractable, but I believe nothing is intractable. Now, I'm not naive enough to expect

that our work will resolve all of those issues, but it's an important step in the process that must proceed if we are to achieve equity and social justice for all of the people on this continent. So, it leads back to that question that I posed right at the beginning, what will it take to achieve that goal. I believe it'll take the involvement, the commitment, and the prioritization of time of every member of this committee to make that happen. So that's what we're going to be doing in this meeting, through the summer and in September.

So, I really appreciate all of you being part of that. Any questions or comments before we move on to our first session related to SIDS and SUID?

MAGDA PECK: Very helpful comments, Ed. Thank you so much for setting the context so clearly.

CHAIRMAN EHLINGER: All right. And let us see -- is Charlene Collier on?

CHARLENE COLLIER: I just got on.

Sorry I'm a little late. Can you hear me, okay?

CHAIRMAN EHLINGER: We can. Good. And I have asked Charlene to moderate the first session related to SIDS and SUID. I'm not sure if you're able to do that, given the fact you just got on.

CHARLENE COLLIER: I'm happy to hop in and, with your support, get through and everyone else's. But thank you for your patience. I had some unexpected travel. Thank you.

SIDS/SUID IN INDIGENOUS COMMUNITIES

CHAIRMAN EHLINGER: Thank you. So, I'll let you take over, but I'm going to make this one statement because I read the Healthy Native Babies Project, and I think it sets the tone. You know, SIDS and SUID -- I'll just quote from them, and then I'll turn it over to you to take it from there. It says, "American Indians and Alaskan Native people experienced SIDS and sudden unexpected infant deaths or SUID more than any other racial or ethnic group nationwide. In

recent decades, the overall SIDS rate in the United States has declined by more than 50 percent. However, racial ethnic disparities remain. In 2017, the rate of SIDS among American Indian and Alaskan Native infants was more than double that of whites. Further, between 1995 and 2013, there was no significant change in SUID rates among American Indian and Alaska Native peoples with rates consistently higher than any other racial or ethnic group. Consistently high rates of SIDS/SUID among the American Indian Alaska Native population show that risk reduction efforts are not addressing the most critical factors, are not reaching AI/AN communities, and are not presented effectively for American Indian Alaska Native people." It really highlights the fact that this is a major problem, a major issue and what we're doing is not working. So that's why we have this session.

So, I'm going to turn it over to you, Charlene, to take it away.

CHARLENE COLLIER: Thank you, and that absolutely sets the tone and what we're charged to do, which is come up with more transformative recommendations that are grounded in what the Indigenous communities are telling us is what's needed. And so, we're really honored today to have a panel to share the background we need on this, and then for our committee to come up with some new recommendations that are progressive and going to be really critical about what has been in place and then what is missing and where we can move forward.

So we have first our team from HRSA, which includes Diane Pilkey -- please correct me on the pronunciation -- and Maureen Perkins, who will be first presenting, followed by Abby Collier, who is the Director of the National Center for Fatality Review and Prevention, and then we'll move on to our final presenter and I'll introduce as we get closer.

Diane and Maureen, are you on? I think you're muted. Diane and Maureen, I guess, need to

be unmuted. Maureen and Diane got you.

Are people able to hear Diane?

UNIDENTIFIED SPEAKER: It looks like she's on mute, but she's figuring it out.

CHARLENE COLLIER: Yeah. And, Maureen, how about you?

Maureen PERKINS: Can you all hear me?

CHARLENE COLLIER: I can.

DIANE PILKEY: Can you hear me?

CHARLENE COLLIER: I think we have Diane.

DIANE PILKEY: I don't know why it didn't work. I apologize. I'll go ahead and get started. Good morning and thank you for inviting us to present. My name is Diane Pilkey. I'm a Senior Nurse Consultant in the Maternal Child Health Bureau in the Division of Child Adolescent Family Health. I'm the Federal Project Officer for the National Center for Fatality Review and Prevention, as well as the Children's Safety Network. And my colleague, Maureen Perkins, is a Public Health Analyst in the same division and

oversees our divisions Safe Sleep and Sudden Unexpected Infant Death or SUID Portfolio.

Next slide.

So, we will be presenting on some of the SUID prevention investments in the Maternal Child Health Bureau, and then turning it over to Abby Collier, the Director of the National Center for Fatality Review and Prevention who will share some of the data collected from Child Death Review teams on Alaska Native American Indian SUID deaths.

Next slide. The Division of Child and Adolescent Family Health houses investments related to advancing health promotion, injury, and violence prevention, and improving and expanding emergency medical service and systems and preparedness for children, adolescents, and families.

Next slide. I think we all know the definition of SUID, but I put it up here anyway. It's the sudden and unexpected death of an infant which often occurs in the baby's sleep area, and

every year about 3,400 babies die from SUID, which includes deaths from SIDS, accidental strangulation and suffocation in bed, and deaths from unknown causes.

Next slide. Between 1990 and '99, families responded to providers' health messaging that recommended infants be placed on their back to sleep, which resulted in a significant decline. However, for the past 20 years, the rates of SUID have remained essentially unchanged. And, as Doctor Ehlinger stated, this downward trend has not been seen in all groups.

Next slide. There are elements of SUID prevention of safe sleep work throughout Maternal Child Health Bureau, including in the Title V block grant program for Visiting and Healthy Start. This slide lists some of the national Title V measures that are related to SUID prevention. 36 states and jurisdictions have chosen to focus on national performance measure five, which promotes safe environments for infants. And states are able to measure their

progress using data from their pregnancy risk assessment monitoring system surveys.

Next slide. This one's a little hard to see. I apologize. This shows the national data from the three PRAMS indicators over time. The blue line is putting infants back to sleep. The green line is placing infants to sleep without soft objects or loose bedding. And the yellow measures whether infants are sleeping on a separate approved sleep surface.

Next slide. The first program we wanted to highlight is the National Fetal Infant and Child Death Review Program. MCHB funds the national center through a cooperative agreement to the Michigan Public Health Institute. The goal of that cooperative agreement is to increase the capacity of Child Death Review and Fetal Infant Mortality Review teams to do fatality reviews, collect high-quality uniform data, disseminate the findings from the reviews and make some recommendations to prevent future deaths. Findings from these reviews can help us better

understand the circumstances preceding these deaths and can lead to improved systems of care and more targeted programs and policies.

Next slide. Just a little bit of background on the case reporting system. This is the National Fatality Review Case Reporting System. It's a free web-based data system established for Child Death Review teams in 2005 with FIMR teams coming on board in 2018. You should have a handout in your materials that describes the system in more detail. Participating states can enter into a data-sharing agreement with the center to use the case reporting system. And the system allows local and state CBR and FIMR programs to enter their case data, summarize their findings. They can download their own data. It also has standardized reports, as well as the ability to create some data visualizations. Currently 47 states are entering data into the case reporting system. And based on the data-sharing agreements with the center, a subset of states allow their deidentified data to

be used to create a researcher database.

Next slide. The National Center is a key resource for collecting information on these SUID deaths. The CDC SUID Registry builds on the work of these Child Death Review programs, and their SUID grantees use the National Center's case reporting system as a basis for their data collection. Their researcher database that I mentioned on the previous slide has detailed information on over 28,000 SUID deaths. Beginning in July, new expansion funds will be available to support the National Center to enhance support to states, communities, and tribes in order to increase the use of a case or warning system for SUID as well as sudden unexplained deaths of children with an emphasis on teams not currently supported by the CDC SUID Registry. Another goal is to increase data dissemination and data-informed prevention activities related to SUID as well as SUDC. This includes producing summary data reports, creating a public-facing data dashboard and increasing the use of the researcher

datasets.

Next slide. MCHB also funds the Children's Safety Network through a cooperative agreement to the Education Development Center. This program supports the work of Title V and state injury programs in their efforts to reduce fatal and serious injuries among infants, children, and youth. The focus is to support improvements in the adoption of evidence-based policies, programs, and practices in priority topic areas related to common MCHB performance measures. The Children's Safety Network does this through training and technical assistance, learning collaborative and resource development such as webinars, fact sheets, publications, and infographics in a wide range of child injury prevention topics.

Next slide. Children's Safety Network has initiated three child safety learning collaborative cohorts with 10 states and jurisdictions who wish to focus on the prevention of SUIDs. You should have a handout on this as

well. Participants in these learning collaboratives receive online learning sessions that offer in-depth guidance on implementing and spreading evidence-based, evidence-driven strategies and programs. They receive customized coaching and technical assistance from national experts, and they utilize an online workspace to report their child safety activities and get feedback and guidance from the Children's Safety Network.

In the SUID collaborative, states and jurisdictions selected the evidence-based and evidence-informed strategies that are most appropriate for their own state's SUID prevention goals. Some examples are listed here. For example, 241 hospitals or birthing facilities provided safe sleep training to healthcare providers. 48 home visiting programs distributed safe sleep education materials, and 52 organizations implemented evidence-based safe sleep campaigns.

Now I'm going to turn it over to my

colleague Maureen Perkins who's going to talk about some of the other SUID investments in our next slide.

Maureen PERKINS: Thank you, Diane.

So, most of our work on SUID prevention is based on the 2016 American Academy of Pediatrics Taskforce on SIDS policy statement and technical recommendations. You'll see some of the recommendations listed here on the slide, and also note that a revised policy statement should be released later this month.

Next slide. So, even though we have these recommendations, there are variations in SUID rates across the states. These variations have been attributed to poor prepregnancy health, tobacco use, access to quality care, socioeconomic inequity, structural racism, and lack of programs and policies that support parents like home visiting and paid parental leave.

Next slide. So, some of our previous work on safe infant sleep, to give background, in 2014 we founded the Safe Infant Sleep Systems

Integration Program, which established a national coalition of various stakeholders called the National Action Partnership to Promote Safe Sleep. We were focused mainly on integrating the messages around safe sleep promotion and breastfeeding promotion. In 2017, we funded the National Action Partnership to Promote Safe Sleep Improvement and Innovation Network, which continued the coalition, added some quality improvement components, and focused on health equity and ensuring our messages reflected the needs of communities.

Next slide. Our colleague Doctor Ashley Hori conducted a study showing that while parents report receiving specific safe sleep practices such as back sleeping, they're less likely to receive information about other recommendations like placing an infant to sleep in a crib, reducing clutter or room sharing without bed sharing. So, we believe some different approaches are needed to help providers more fully educate and counsel infant caregivers.

Slide. So, our new SUID prevention

program launches next month. It's been awarded to the American Academy of Pediatrics. The goal is to reduce racial and ethnic disparities in SUID. We will be focusing on using the data and findings and recommendations from FIMR and CDR reviews, helping pediatric providers to provide counseling, implement community action teams and support them to offer more culturally responsive care.

Next slide. Here is our contact information for myself and for Diane. And I will now turn the presentation over to Abby Collier, who's the Director of the National Center for Fatality Review and Prevention.

ABBY COLLIER: Thank you very much, Maureen. Good morning, everyone. It's such an honor to be here with you today sharing some information that we have gleaned from Child Death Review teams.

Next slide, please. One second. As we are waiting for the slides to come up, I just want to acknowledge my colleague Rosemary Fournier is here with me as well today and is our FIMR expert.

And although I'll be sharing data specifically from Child Death Review, we know there's significant implications on the FIMR side as well.

Next slide, please. So, Diane very succinctly talked about the case reporting system and how it's used. Just a visual to point out it's used in 47 states for Child Death Review. 18 states use it for FIMR. But I think the key message on this slide at least is that every state uses it a little bit differently. Some states enter 100 percent of their cases, other states enter 10 percent. Some states only enter certain causes or manners of death. Some states enter them all. And that can make it challenging to use case reporting system data. But, despite its limitations, it is a very unique and valuable data set.

Next slide, please. We do want to point out that data from the case reporting system are available for research purposes. Sleep-related infant death is the number one researched topic on Child Death Review data, but anyone

affiliated with a research institution can submit an application and access the data to conduct your own research.

Next slide, please. All right. So now we're going to jump into the actual data that we ran out of the case reporting system. As Diane said, we maintain the case reporting system, and, additionally, we have what we call a research data file. That research data file contains fatalities where the state has given permission for them to be shared. We found 28,110 infants who kind of met the criteria for an unexpected infant death. So, they were SIDS, SUID, an ASSB or an undetermined. Of that 28,110, 866 of those infants had a race of American Indian or Alaska Native listed. I do want to point out that in our data we've recently started recoding and representing racial data a little bit differently. We discovered that, in particular, American Indian infants or children were overrepresented in our multiracial group. They comprised about 30 percent of that group. And in order to better

reflect the risk in the community, we have defaulted our data analysis to pull out American Indian Alaskan, Native children, regardless if they have another race listed. So, the data that we're going to share with you also includes children or babies where the race was just American Indian or Alaskan Native, but it also includes cases where it was American Indian, Alaskan Native, and maybe black or white. This is a little bit different than how we handled the rest of our data, but it was consistent with feedback we received from some subject matter experts, some of who are with us today.

The last thing I want to point out about these data are that the missing and unknown amounts vary depending on the question, and they are excluded in the following analysis. So, what you'll see is only data presented as yes, no, or whatever the variable options may be.

In preparation for this meeting, we knew that there was a number of specific data points this group was interested in.

Unfortunately, we were unable to provide data on three of those. The first was postpartum visits. It was missing 96 percent of the time. For infants being born drug-exposed, it was missing 70 percent of the time. And infants experiencing neonatal abstinence syndrome, that was missing 84 percent of the time. There's a number of reasons why we think these missing are so high, and some of them being that these are newer questions to the case reporting system. But we did want to point that out for you.

Next slide. There were no differences between American Indian, Alaskan Native infants and other races for age or manner of death, so you won't see those displayed here just for lack of time. What you see up here are factors present in unexpected deaths. In the first circle is a history of maltreatment. This is asked for all cases in the case reporting system. 21.9 percent of infants who had a race of AI/AN had a documented history of maltreatment compared to 12 percent of infants of other races. We went on to

look at overheating, as that's a risk factor from the AAP. 8.4 percent of American Indian and Alaskan Native infants had overheating indicated at the time of death compared to 44.2 percent of all other races. If we look at breastfeeding, 70.9, so 71 percent of AI/AN infants were breastfed at least once, and that compares to 57.1 percent of all other races. And then for birth weight, we found that 16.3 percent of AI/AN infants were born weighing less than 2,500 grams compared to 21.9 percent of all other races. So, you can kind of see in the slide higher percentage of reported breastfeeding, fewer infants being born low weight, but potentially a higher history of maltreatment and more likely to experience overheating.

Next slide, please. So, in this next slide, we wanted to talk about smoke exposure. I know there was sort of a lot of interest in that. So, for smoking during pregnancy, the numbers were actually very similar. 49.3 percent of infants were exposed to smoke at any time during the

pregnancy, and then compared to 48.8 percent of all other races. And then after delivery, there's a little bit of a difference in smoke exposure here. 60.3 percent of AI/AN infants were exposed to smoke at some point after delivery compared to just under 50 percent of all other races.

Next slide, please. One of the questions was, was the infant placed in a new sleep environment. And you could see, you know, 23 percent of AI/AN infants were in a new environment, but the numbers are very consistent with what we see for all infants.

Next slide, please. So, room sharing and surface sharing, I feel like this is often the big question when we start to talk about -- particularly sharing the message of sharing a room but not a surface with infants. So, we found that 77.7 percent of AI/AN infants were room sharing compared to 71.4 percent of all other races, so a little bit higher percentage of AI/AN infants were room sharing. If we look to the middle box, that's surface sharing. So, we found 69.3 percent

of AI/AN infants shared asleep surface, compared to 65.4 percent of all other races. So again, it's a little bit higher, not too terribly different. And then this last one is sort of the AAP recommendation of share a room but not a bed, and we found 14.9 percent of AI/AN infants were room sharing, but not surface sharing compared to 16.4 percent of infants of other races.

Next slide, please. So, here we looked at the sleep surface, where was the infant placed to sleep. And, for the most part, you can see there is a fair amount of consistency between AI/AN infants and all other races. The one thing that was sort of notable was the percentage in adult bed is higher here. And on the previous slide we pointed out that AI/AN infants were slightly more likely to sleep on a shared surface. So, this is actually showing us consistency in the data, which is a good sign that the data are being entered correctly. So, I think, you know, you could -- it's safe to say that AI/AN infants might be more likely to be in an adult bed. I do want

to point out that crib, slash, bassinet really is any sort of portable crib too, like a pack and play fits into that definition. Couch or chair also includes pillows. And then the items that fall into other are things like a waterbed. That's really what's in other.

Next slide, please. So, one of the things that we talk about when we share our data is that we know data quality can be lacking. And, you know, there's a number of instances where we're asked for data, the teams try to collect it and they are unsuccessful. So, people ask me often how could you fix that, and I think the answer to that is twofold. First is to improve consistent access to records throughout the US. As the laws stand right now, they're typically state-based and open to interpretation. So, there's a lot of variation, even for states that have really strong legislation. And then the second piece is resources to support data collection and entry. Through our work with the SUID and SDY case registry that Diane mentioned,

we have seen those jurisdictions that are funded have a pretty drastic improvement in their data quality and completeness.

Next slide, please. Again, thank you so much for the opportunity to come today and share with you some of the data from the case reporting system.

CHARLENE COLLIER: Thank you, Abby. So, we'll pull up our last presentee, and then we can open up for some questions. I know there are a couple in the chat just mentioning, talking about infants being ever breastfed. So, we'll pull up our next speakers. So, we're really privileged to have Shira Rutman and Kendra King Bowes joining us from the Miami Environmental and Energy Solutions. And they work very closely with research on SUID and SIDS in the Native American population. And we are glad to have you join us, and your full bios are in our program book. But we'll let you jump right in, so we'll have plenty of time for questions.

SHIRA RUTMAN: Thank you so much, and

thanks to the presenters who shared just before me. It's really interesting to see some of those data. And I'm grateful to be here. My name is Shira Rutman, and I'm a consultant with the Miami Environmental and Energy Solutions, which is owned by the Miami Tribe of Oklahoma. I'm sorry to say that our Managing Director Kendra is not available to join me today, but I do see that one of my cherished colleagues Lee Tanner is here and is a partner of ours on this project.

So, I'm here sharing information that was gathered as a part of the Healthy Native Babies Project, and this was previously funded by the NICHD. I'm including a QR code here so that you can see some of the background of the project. So, for those who are less familiar with that technology, you just point your phone camera to that icon, and it should bring up a link to more information about the project. So, I do want to acknowledge, in addition to Lee, the rest of my colleagues on this project, Geraldine Simpkins, Kristin Hutley, and Marie Zafir. And I want to

say that I'm dialing in from San Francisco, which is the ancestral land of the Ramaytush Ohlone. I'm also an analyst at the Philip Arlie Institute for Health Policy Studies at the University of California San Francisco. And I want to thank Doctor Palacios for inviting us here today. We're going to be talking about insights on safe infant sleep in Native communities.

Next slide, please. So, between July of 2020 and May of 2021, our team conducted key informant interviews with 16 individuals, and these were program directors, healthcare and social service providers, health educators and a spiritual elder, all who are working to address safe infant sleep in Native communities. They were based at tribal organizations, at hospitals, at Indian Health Service locations, urban Indian health programs and university and state-based agencies serving Native populations. They were located in eight different IHS regions, so we were lucky to really capture a broad range of experiences and perspectives with this group of

experts. And there was so much rich and critically important insight shared with us in these interviews, I'm only going to be sharing some highlights with you all today. We are hoping that the full report summarizing our findings will be posted on the NICHD website at the link again at the QR code listed sometime in the near future.

Next slide, please. So, while our interviewees were a diverse group, we actually heard very consistent themes across them, and these really highlighted the systemic risk factors for SIDS in Native communities, and the importance of viewing the context for communities as well as individual families. They talked about how the history of colonization, ongoing oppression and structural racism continue to impact communities' efforts to reduce SIDS risk. And these experts also spoke about the need for policies that address common and persistent challenges, especially in housing and healthcare. I'm going to share more about each of these next, and I know some of the data, as I interpret it, that was

shared by my colleagues just before reflects this as well.

We asked these experts for recommendations, and again heard some consistent themes, and I'm going to highlight these now, and then I'll talk more about them. The importance of early and ongoing education on SIDS risk reduction was one, and really starting with birth workers and home visitors during pregnancy, and including all extended family, especially elders. They also recommended strengthening collaborations across providers and educators for consistency and persistence in safe sleep messaging and improving on training for all providers serving Native communities. They recommended building on cultural strengths, which included traditional activities and culturally specific care. And really Native communities and organizations should be funded to design and lead all of these efforts.

Next slide, please. So, looking at the data in a bit more detail, first I'm going to share some of the barriers and challenges that our

experts identified for us, and then I'll talk about some of the strengths that were shared.

Next slide, please. When asked what makes it difficult for Native families to practice safe infant sleep, one participant summarized the most common issues saying there are challenges in the built environment, living in multigenerational families, living in homes where there is substandard housing babies may not have a place to sleep safely, and parents may struggle living with elders when they try to insist on or demand smoke-free environments. The experts we interviewed all underscored the need to address the root causes of SIDS risk factors experienced by Native communities, including taking a holistic approach to safe infant sleep by prioritizing funding for policy-level interventions in addition to individual-level approaches with families. We also heard that the COVID-19 pandemic has exacerbated housing and healthcare challenges for these families.

Next slide, please. Within the

challenges summarized in the quote that I just read, overwhelmingly, the most common shared was a lack of money and space for a separate sleep surface. And these are a few quotes highlighting this issue. People are limited based on what they can afford. There are people who are couch surfing. It's a much harder conversation with families who don't have the spaces to reinforce safe sleep practices.

Next slide, please. Additionally, we heard about the impact of housing insecurity, especially among Native youth, on access to safe sleep spaces, which is reflected in this quote. It says I think for the young parents not having a home of their own, kind of going from home to home, whether it's the father's parents' home or the mother's parents' home, moving temporarily from one location to the other, I think that's part of why cribs are not being used, besides the financial factor. And again, I was interested to see some of those percentage differences that were shared by Doctor Collier to this effect as well.

Next slide, please. The second most common challenge to safe infant sleep described in interviews with our experts was barriers to healthcare. For some clinics in tribal areas, there is no inhouse prenatal care or obstetrician, and obstetricians can be a long distance from tribal areas. Case managers at Indian Health Clinics may not receive any communication from an obstetrician, which was explained by one key informant who said you may see one family medicine doctor who takes care of you before baby comes, another one who delivers you and then me for pediatrics after baby arrives. It's not always a consistent message across everyone, and that can be confusing.

Another issue within healthcare described by a few of our participants was cultural insensitivity and racial incongruence between healthcare providers and patients that leads to a lack of uptake of safe sleep recommendations. And I know this committee has drafted some recommendations related to focus on

educational pipelines for Native people in medicine and other scientific fields, which I think is relevant here.

Next slide, please. One key informant explained challenges with nonnative providers trying to serve Native families as follows. When it's coming from someone like me, who is not Alaska Native, when I say let's get a bassinet and put the baby there, it can be taken as me saying the cultural practice is inadequate. It can come across as me challenging generational ways. It can come across as condescending, and almost a form of cultural oppression.

The primary recommendation around this issue was focused on cultural sensitivity training for healthcare and social service providers to help address barriers for families accessing services and wanting to engage in traditional practices, traditional healing practices, in particular. Part of this is the need for education and understanding about the history of colonization in the United States, and the ongoing

impact on Native people, including infant outcomes like SIDS.

Next slide, please. Next, I'll share a bit about recommended approaches for safe infant sleep in Native communities that our experts shared with us.

Next slide, please. Several experts that we interviewed also spoke to the value of a risk-reduction approach, and one said my lessons learned really are lessons about the importance of a harm-reduction approach. Not everyone will be able to meet all of the requirements that constitute a safe sleep environment. It's important to meet people where they are. Patient-centered care, which also encompasses holistic care was described by several of the experts we spoke with as an essential approach to safe sleep promotion within Native communities, and one of them explained this as making sure you can ask questions and have conversations without making people feel shame. I participated in the NAPS project back in 2014, and I know that these

conversations are a big part of that focus. And patient-centered care is defined as when an individual's specific health needs and desired health outcomes are the driving force behind all healthcare decisions and quality measurements. Patients are partners with their healthcare providers, and providers treat patients, not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective. This holistic approach is also in line with Native traditions.

Next slide, please. Multiple experts we spoke with recommended early and consistent education, including the best timing as during the prenatal period. Or, if that connection is not made, then before the family leaves the hospital or birthing place, and they highlighted opportunities for birth workers to include safe sleep education. A couple of experts commented as follows. Education should be provided by obstetricians to give the moms time to think about it, look it up for themselves and create plans

before the baby ever comes. Another said we could be utilizing individuals that work with moms that do birth work, our birth workers like midwives, doulas, and groups who support women postpartum. Those groups could really be solid places where we could talk more about harm reduction and supporting families.

Next slide, please. Our interviewees noted the need to engage fathers and multigenerational caregivers. One said, "we really need to be creative in including the father. Everything's mom, mom, mom, and fathers need to understand that they have a responsibility too. Including that father perspective, I think, would be helpful." This next quote says, "there are many people caring for an infant. It is really important that the education extend beyond the mom and the dad. Bring in grandma, grandpa, aunties, uncles, the whole extended family."

Next slide, please. Several experts we spoke with commented on the need to support healthcare and social service providers and

educators in safe sleep education. This included ways to foster collaborations across providers and organizations such as creating a forum for sharing lessons learned and ideas for mutual support, providing ongoing professional development, including the training that I mentioned previously. Promoting continuity of care through policies and practices for referral follow-ups was also recommended.

Next slide, please. Finally, I want to go over some of the strengths that were shared when we asked about traditional and cultural practices to support safe infant sleep in Native communities. Next slide. The most common response when we asked about traditional cultural practices for safe infant sleep in Native communities was the strength of the extended family. One of our experts shared this quote. "Many family members take an active role in helping to raise these children. Really the community helps raise them." This also encompasses social support. A few of our experts

talked about the opportunity for community events and support groups as ways to build on community strengths for protective factors. One shared the following. "When families are connected to community and to other people in the same phase of life that can support each other, those are places where safe sleep messaging and harm reduction could really be happening."

Next slide, please. These experts also talked about how traditional practices and teachings can be opportunities to build on strengths-based approaches to education, and to incorporate education about safe infant sleep. Some of the examples they shared were feeding, baby wrapping, dancing, traditional dancing, breastfeeding, powwows, gifting star quilts and sacred tobacco. We also asked about the use of cradleboards specifically, and most of our experts shared that there was a high level of interest in and use of these traditional items. You can see a picture of that in this image here. A cradleboard is a baby carrier to keep baby safe, secure, and

comfortable while at the same time allowing the mother's freedom to work and travel. They consist of a frame made of natural materials and are decorated with materials and in a style that varies from tribe to tribe regionally. It is flexible in use. It's decorative and protective. And cradleboards, I should note, should not be used in lieu of car seats, which is always a part of the discussion in introducing these items.

Next slide, please. The theme of culturally specific care was one of the key lessons shared with us from the experts we interviewed. One said, "there are over 500 tribes in the US, and they all have things that are very unique to them. It makes it challenging, but Native people want that connection, and people outside of Native community, work and cultures may not understand at all how important that is." Again, this really highlights the importance of integrating and building on cultural teachings in safe infant sleep education and allowing and supporting and funding Native communities and

organizations in leading this work.

Last slide. Sorry. The last quote I'll share is on the next slide, I think. The last thing that we want to share from our experts is the diversity of practices and traditions across Native communities and within families, which are protective for safe infant sleep. This can be from tribe to tribe, urban area to rural area and in different families, some of whom are traditional and others that didn't grow up with traditional teachings. This theme really highlights the importance of tailoring efforts to the communities and individuals being served, and, again, for these efforts to be community-led. I don't think I can say that enough.

I'll read this quote. "We have far more strengths -- in our communities, within our cultures, within our languages, and within our ceremonies, we have far more strengths than we have barriers or challenges, and to draw on those is really important and connect those to whatever we are trying to affect change in is really

important." And I think that it's really important to end on that note of building on the strengths and listening to the communities that have the answers to these challenges for them.

Last slide, please, is my contact information is here again. I have the QR code, which will bring you to more information about the Healthy Native Babies Project. And my e-mail is listed there as well as a little background information on some of my work listed on the UCSF website. I'm happy to be in touch with anyone to follow up questions or more information around the work that we do and the work that I've done in partnership with Native communities. Thank you for giving me the chance to share today.

CHARLENE COLLIER: Thank you so much, Shira. That was amazing information and very powerful, and I think it certainly sets the foundation of where we need to start as a committee for our recommendations.

So, I'll just ask all the panelists to come back on camera, if you're able to, and then

if any of our committee members want to open up with any questions or comments. Yes. I see Magda's hand up. Go ahead.

MAGDA PECK: I'll give a start. First of all, brilliant. I'm delighted with this session and for all the preparation that went into it, and the combination of both the qualitative and quantitative data.

And I'm curious about the disconnect between the surveillance system of Title V data first presented in measurement five by the 36 states that do collect this, the data that comes from the Fatality Review systems, which are contextual data, but not a surveillance system, and then the qualitative data that can come from the experts when you ask people directly what's needed.

And one the disconnects I was hoping that maybe we could have a conversation around that relates to an earlier session at SACIMM in spring, which has to do with housing. And I was just noting that in the data that are collected

both by Title V performance and even the measurements and that which is taken in the Fatality Review, I just don't see any systematic focus on the context of housing instability and the expectation that our educational materials around safe sleep will fit a quite different reality, especially accentuated by COVID that Shira brought up. So, here we hear from the experts and what's happening that housing is a big deal, but I don't hear anything asked about the housing context but only this specific surface and whether you're sharing with mom. And there seems to be a disconnect. So, I was wondering how can housing context be brought in as just one example of what we're asking and collecting systematically, and what is the lived experience and reality that we're hearing from the field. And maybe if the folks at MCHB could start first, and maybe Abby could go second just to how do you -- how do you respond to what you're hearing the field and folks say?

CHARLENE COLLIER: Thank you, Magda.

MAGDA PECK: I know you know it, but how do we collect it? How does the data --

DIANE PILKEY: I think that's a really good and important question. And, actually, I was going to defer to Abby because the center has been making efforts where they've added questions to the case reporting system about life stressors, and also, they do collect some data related to that on housing. So, I'm going to defer to Abby to address what we've been doing in that context to collect better data.

ABBY COLLIER: Magda, I saw your hand go up. Did you want me to wait?

MAGDA PECK: I'm going to come back to Diane with complete respect, because here we had Doctor Cho with us talking about trying to build the connections with Housing and Urban Development and how housing and health are essential for health impact. So, I'll ask if you have any connections on your end at the cabinet level with housing around systems and infrastructure and training and cross-sector connectivity. So yes,

pass that to Abby, but that's what I'm hoping that you'll also be able to come back so we build on our earlier SACIMM work.

DIANE PILKEY: And I'm going to refer that up the ladder in the --

MAGDA PECK: I'm putting you on the spot.

DIANE PILKEY: -- Doctor Warren, about the connections that are being made, you know, at a broader level than in our individual programs.

JACOB WARREN: Right. And Doctor Peck, happy to weigh in. So, we do have a relationship within. And I think that relationship has really been growing over the past year, both around maternal and infant health. So, with the administration's work on addressing the maternal health crisis, HUD has been a partner with us. And we have a federal workgroup of federal partners around infant mortality in this question of getting to infant health equity by 2030, and HUD has been there as well. So happy to take the comments we've heard today back to that

conversation. But they are there, and very eager to be not just at the table but engaged.

MAGDA PECK: I'm so happy to hear that. I just want to say if the data agenda and the infrastructure and the cross-connectivity of what we're learning and surveilling, if the data could speak to each other, we might have a more robust picture of how policy can change and know the changes that we make are making a difference that we want.

JACOB WARREN: So, I think that's really important. One thing I will say on the data piece -- this was new to me. It may not be new to all of you. Our HUD partners shared with us the time in our lives where we are most likely to be unhoused is the first year of life, and that was a surprise to me, but I think really insightful as we think about moving forward.

CHARLENE COLLIER: Joy, you have your hand raised?

JOY NEYHART: I do. Thank you. I really appreciated Shira's presentation. I work

with the State of Alaska Maternal Child Death Review. And what struck me when I first started with that committee was that there weren't people at the table from the communities where the deaths were happening. And so, seeing what you guys do in California to bring people to the table is really encouraging, and it -- I'm wondering if at some point you could come and speak to our group in Alaska.

SHIRA RUTMAN: Thank you. Yes, I agree, and I probably said it many times that, you know, having the -- so I'm not a Native person. And, you know, I'm an ally in work, been working in partnership with Native people and Native organizations for a number of years and can only do this work -- you know, I'm in an honored position to be able to share the voices of the experts and work with my Native community partners to share those voices and can really only, you know, represent folks when I'm asked to do that, but I would be happy to continue those conversations and reconnect with some of those

colleagues. And we do have a person on our Healthy Native Babies team Kristin Halfe (phonetic) who's an Alaskan Native woman. Sorry. I'm forgetting her tribal affiliation at the moment. I believe she's Athabaskan, actually. Anyway, so I'd be happy to reconnect with some of those partners and try to make recommendations for you about whether myself or someone else might be able to come speak with you. But I really appreciate your takeaway from that and taking that opportunity.

CHARLENE COLLIER: Thank you so much, Shira. Doctor Menard?

JOY MENARD: Thanks to all the panelists. I'm learning so much from your minutes. I guess what I'm hearing, you know, 500 tribes all very unique, diverse communities and the need to honor those differences is really important to this work. And then I hear the absolute need for cultural sensitivity training, you know, for our workforce at every level, and the confusion that comes when practices and best

practices aren't conveyed consistently between the prenatal care provider and the, you know, maybe the intrapartum nurse or the pediatrician, and the confusion that comes with that.

But I'm wondering, and I think my question is directed towards Shira to comment, is how do we reconcile that, the need to really kind of meet the broadly diverse, yet come together with some recommendations and potential policies and support that will meet that broad, you know, kind of diverse community that we need to support?

SHIRA RUTMAN: Yeah. Sorry. I think I heard what that was. That was a question to me.

CHARLENE COLLIER: If you can, yeah.

SHIRA RUTMAN: So, I know that there are, as we heard from the partners that we work with, that there are some of these recommendations around, especially as the last slide that I shared describes, you know, tribal communities are as diverse as any other, you know, group. And so, you know, some folks are connected to their traditional practices, others are less so. It

depends on the community and the family that they've grown up in. Some folks are seeking out those connections, even if that isn't something that they've grown up with. And so, I would say that really creating opportunities for some of the organizations that have been serving broad -- that have been serving tribal people and communities for a long time -- I'll share one example, which I actually should note as a correction in the agenda that you might have seen. I'm listed as affiliated with the Urban Indian Health Institute. I did work at the Urban Indian Health Institute for many years early on with Lee, actually, and some of the work that she's done over the years, but I don't anymore. However, they are one of a number of tribal epidemiology centers funded by the Indian Health Service and others who are just one example of partners who serve a broad range of regions and tribal people who could support designing and supporting efforts to implement diverse tribal people. So, I would say that really, ideally, those interventions and policies

should not be designed just at the national level, but that should really be designed in partnership to be implemented with regional partners as well.

But also, many of the recommendations that we heard are relevant across Native people about how to take that approach. So, I think that there can be really a combination of doing that and -- and the fact that the tribal people are divers. Should not be a reason to not take those steps that we know can be effective in moving forward. And I'll just note, as I've seen the HUD comments and comments on housing, I am familiar with the Broken Promises Report that was published in 2018, which has quite a bit of detail specific to the housing issues and recommendations by the -- I'm sorry. I'm going to mispronounce the name if I try to make a guess, but you can certainly Google the 2018 Broken Promises Report. And, again, there's a whole section of recommendations. So, this is certainly not the first time that we're hearing the connection to health outcomes and housing. And so, I'm so delighted to see that

folks are picking up on the potential for how to integrate that into these recommendations.

CHARLENE COLLIER: Thank you again.

Doctor Palacios?

JANELLE PALACIOS: Thank you. Thank you to the presenters. That was really engaging and has shared quite a lot of information for us to consider. And I want to also thank Abby and Rosemary for the work you did in determining who was included in the analysis that it was multiracial American Indian and Alaskan Native people were included in that, because as a -- as inherited from our colonial history, there are definitely big identity concerns related to that. So, thank you for including multiracial Native American people, regardless of all the other ands and ands and ands and ands, and definitely I'm one of them.

But I'm just kind of thinking what -- you know, going back to what Ed said earlier and then also going to forward of what we've heard today, what I'm wondering, what other questions,

what other variables are needed, Diane and Abby, on these reviews, on these surveys, on these forums that will get at more of the social determinants of health, contextualizing the infant safety, right. And as we heard from Shira Rutman today, the experts who were contacted and give their lived experience that, as a provider, someone saying, oh, you just need to buy a crib and place it here, and knowing that this family or community, you know, has high housing instability, that the reports or that the variables shared with us show, you know, bed sharing, or space sharing, you know, room sharing was high likely for Native American infants and families. But what else is missing? It was good to see that there was something indicative of maltreatment or abuse or violence in the home. And, of course, that's just what was reported or disclosed, right? That's not at all telling us the full picture. But what other variables could be added? Because the way sometimes that the data is presented, again, it puts the blame back on the family, well, they were

sharing -- they were co-sleeping, or they were smoking postpartum. Well, there's a lot of context to that, as we heard, the multigenerational families living together. So, I'm wondering what other variables could be added, and, if you have a thought as to, like, where you would go to confirm, maybe it's additional lived experience, additional community experts or partnering with Shira's group to understand what other questions could be added. So, thank you.

ABBY COLLIER: That's such a great question, Janelle. I put in the chat the link to the data form that we use. It does show you all the variables that we collect. And about two years ago we added a section called life stressors that's meant to get at those contextual factors we're talking about, housing instability, neighborhood violence, relationship discord, for older kids looking at things like transitions in and out of school, in and out of child welfare, juvenile justice, etcetera.

We would really welcome any feedback on

how to improve and expand this section. We added -- actually, today, the next version of our data system went live this morning. And in this new version we have a section on medical life stressors. We're hoping to better understand the barriers that families experience. But if you look through these and you have suggestions, we would absolutely welcome them. And as we start to think about version 6.1, which we get just a tiny break before we start planning for that, I really love the idea of engaging with some folks with lived experience to hammer these out a little further. So, thank you so much for that recommendation. So, I would just say we're getting there. We're excited about these, but it's -- we're not all the way there yet. It's a good start.

JANELLE PALACIOS: No, and that's -- that's exactly the whole point of we are -- understanding that context is so important, and I love -- I was just reviewing as you were sharing, Abby, so that it's not race, which has been the

issue for much of the research on disparities has been placed on race. It's all the other factors. So, it's also the racism. That's really what's at stake. So, thank you. It's wonderful, and I will be sharing with colleagues.

CHARLENE COLLIER: Ed, your hand raised?

CHAIRMAN EHLINGER: Yes. I have more of a comment. We've talked about the importance of narrative, and what the narrative is and how that shapes what we do. And so, I hear some discordance in the narrative here. We hear the story about how it's all the social factors that really impact SUIDS and SIDS, and yet we talk about patient-centered care. Why aren't we talking about community-centered care? Because all health is within relationships.

And, similarly, the grant that was given to address SUID going to the American Academy of Pediatrics, I mean, I don't know all of the reasons behind it, but it medicalizes this issue about it's an individual problem when really

it's a community problem, the housing, the racism, the environmental contaminants, the economic insecurity.

So, I think we need to think about how we shape our conversation, and how we change the narrative. You know, for me, I try not to use -- I know we want to focus on the individual and give good care, but I think we need to do it in the context of the community. So, I think, you know, think about that narrative as we move forward.

CHARLENE COLLIER: Doctor Peck?

MAGDA PECK: Two very more granular questions if I could. And, Abby, I think this one comes to you. First of all, thank you again to the National Center for running special analysis. Thank you for letting us know that they are available and being open to change. Can you give me information about all of the both Child Death Review, of which there are hundreds, and the FIMR sites in the country? What proportion of the community review teams include tribal members, Indigenous people? Can we -- do we have -- do we

have a sense that built into the sentinel event review methodology, the fatality review process, they're not just people we consult with? This is Ken Harris' comment in the chat. Thank you, Ken. But there's actually at the table of the reviewers who are interpreting the data that are coming out, can you give us a sense of what the demography is of the composition of death review teams in both fetal, infant and Child Death Review that would give us confidence that there are Indigenous perspectives and lived experience at the table? So, that's one question of data about the infrastructure very specific.

And the second is, if we're doing this kind of questions and surveillance -- we were asked to consult on PRAMS a year ago. As you think about making systems more robust, and one of the recommendations that Shira Rutman came out with, and it was brilliant, shared in the last part, from listening to experts is, what about moving shame to strength, and what are the strengths that we build on. So, a generic

question in the whole process that we're doing here of data and specific to SUID and SIDS is, do we capture any data on family strengths, on community strengths. Like there's a whole methodology that has been created in terms of strength-based and acid-based methodologies, but we tend to think about risk and negative outcomes. So, I'm wondering is this an opportunity to restructure the social DNA of our surveillance systems of our case review systems to also highlight some of the more protective factors that build on cultural and traditional strengths in addition to practices like breastfeeding. Those are both very specific questions, so good luck.

ABBY COLLIER: Thanks. Both good questions. I can answer the first one with sort of a nonanswer, I'll get back to you. The participation from American Indian Alaska Native communities on Fatality Review teams is incredibly variable. We actually have a virtual national meeting later this week, and I'll ask the question and see what people say around current

participation. That doesn't speak to quality of participation, but we'll get a number.

We do work diligently with tribes and with the community or the state-based review team to help build collaboration, or to help build autonomy for tribal specific Fatality Review. We can go either way. So that's a we'll get back to you.

Your second question on focusing on strengths, we agree with you completely, and, in fact, two years ago modified our data form to capture not only risk factors, but also protective factors. And there still needs to be a lot of education around that because, you know, the thinking is typically a child died, nothing could have gone right. But there are protective factors to be found in there. So again, it's another we're started. We're not there all the way. And we get a -- we're going to take a little six-week break, but then we'll be right into version 6.1 where we love this feedback because we want to make every version a little bit better.

MAGDA PECK: And to the degree you can be informed about, what specific to American Indian, Alaskan Native Indigenous peoples strengths so that how you decide what questions are asked can capture that -- and I go back to Ed's original comment that, if we capture those strengths for this group of essential folks, it could also be informative about extending those strengths in other populations. So, ask before you change, and an opportunity for taking the expert input that Shira Rutman talks about and bringing and informing what our surveillance and case review systems can have, and that would go to Title V performance measures as well so that there's an alignment that begins to happen.

CHARLENE COLLIER: Thank you so much, Magda. Those are great points and an excellent conversation. So, I want to thank all of our panelists. We are at time. Please continue to enter your comments in the chat and refer to them. There's excellent points within them. And so, again, thank you all for really excellent

conversation and a jumping point for our recommendations we're going to work on for tomorrow.

Doctor Ehlinger?

CHAIRMAN EHLINGER: Doctor Collier, thank you for moderating that. Thank you for the presenters. This was a great session. I particularly appreciate that Diane and Maureen and Abby actually changed their schedule. I know they have a big meeting coming up and had to sort of fit this in, so I really appreciate the effort to make that happen. And certainly, Shira, you provided some essential information that was really helpful. So, this was really a nice mix of data and story and perspective that will really be helpful to us. And this is one of those issues that I -- you know, we would be -- it would be public health malpractice not to talk about SIDS and SUID when we're talking about, you know, First Nations moms and babies. So, this helps us with that kind of information. So, thank you very, very much.

FEDERAL UPDATES

CHAIRMAN EHLINGER: So now we're going to move on to getting a federal update, and in the agenda, it says Lee Wilson. I'm not sure, Lee, if you're going to do it, or if you're going to be bring in the secretary to do it or --

LEE WILSON: I am not going to bring in the Secretary. When it comes to federal updates, my understanding was that we were going to do a bit of a round robin with the various staff, ex-officio members who may want to provide a little bit of an update on the work that they're doing.

I have some updated notes from those activities that are going on within HRSA in particular, the Maternal and Child Health Bureau. So, let me just jump in here. It has been a busy few months, and I will provide a little bit of an opportunity when I pause for Doctor Warren to give updates on our involvement and engagement at the department level with the formula shortage issues.

But first just on a on a program operations standpoint, wanted to let you know that

our Maternal Infant and Early Childhood Home Visiting Program make the awards and state, Maternal Health Innovation awards have gone out, the announcements for those. HRSA announced approximately $16 million to strengthen the MIECHV programs, through seven awards supporting eight different states. These awards will advance data and technology innovations to support positive maternal and child health outcomes both in states and communities and will focus on addressing health disparities.

Also, we had announced the availability of $9 million through the State Maternal Health Innovation and Data Capacity Program to expand the State Maternal Health Innovations Program and reach additional states. This program supports state-level development and implementation of proven strategies to improve maternal health and to address maternal health disparities. The competition closed on the 13th, yesterday. We received a number of applications, and we'll be reviewing those applications for making awards by

the end of this fiscal year.

Additionally, HRSA's pleased to announce that on May 6 we put out the launch of the Maternal Mental Health Hotline, which is the new confidential toll-free hotline for expecting and new moms experiencing mental health challenges. We had received an initial $3 million investment for this fiscal year to launch the hotline, and it was launched on Mother's Day on May 8. Counselors are available 24/7 to provide mental health support nationwide. As I said, it's 24/7, free, confidential before, during and after pregnancy. And callers have phone or text access to professional counselors, realtime support and information, response within a few minutes 24 hours a day seven days a week. There are resources available as well, referrals to local and telehealth providers and support groups. It is a culturally sensitive support in Spanish and, I believe, 60 other languages for interpretation services. As I said, yes, counselors speak both English and Spanish. We are developing materials

that will go out alongside the hotline so that there are call numbers available at lots of different sites, also for individuals to have -- we're exploring various options, but like a magnet for your refrigerator as a reminder of the number, those sorts of things. And we're making contacts with our grant providers and other organizations to be able to have on-hand referral materials. So, we're very excited about the hotline. There's been a lot of attention on this. Just for your information, it has not been broadly launched everywhere in all of the social media. Because it is a new hotline, and because we were developing the system, going through all the security measures as a federal agency trying to do this, we have been incremental or phased in our approach to doing this because we want it to launch and to be good. We're very pleased with the very short period of wait times, much lower than industry standards as we are ramping up this hotline for services to others.

I also want to mention that the

agencies within the department have issued a joint letter on May 25 to states, tribes and jurisdictions encouraging them to prioritize and maximize their efforts to strengthen children's mental health and wellbeing. The letter was signed by HRSA, SAMSA, CMS, CDC, ACF and ACL, and it outlines HHS' plans to support and facilitate state-level coordination across federal funding streams to advance and expand mental health services for children. We can -- if there is further interest in this, we can upload some additional information about the programs that are engaging in the partnership, and we can provide that to you, if you like.

I also want to mention that we have been working with our Healthy Start Program to continue our efforts in the area of supporting doulas. And we had announced competition, again, for supplements to the Healthy Start Programs to provide community-based doula services through our grantees. These will be women during the period -- serving women during the periods of pregnancy,

birth and three months following their delivery. Award funding will go to cover the training and the services that they provide with a special focus on trying to encourage doulas as a profession and something that is supported as a profession by the Healthy Starts, granted the Healthy Starts can propose how they would like to engage doulas, whether that be through contract or on staff. But we like the idea that we are promoting this as a reasonable profession that is being supported at the community level.

Also, we have been running a competition for our Catalyst Program for Infant Health. The application period closed on September 26. This new program will support the implementation of existing action plans that apply data-driven policy and innovation strategies to reduce infant mortality disparities in specific counties and jurisdictions. This program aligns very specifically with the message that Doctor Warren shared about his vision for addressing infant health equity and trying to reduce the

number of infant deaths in communities that are experiencing disparities so that we can achieve or move more deliberately towards equity across the races in our infant health outcomes.

Finally, I just want to give you an update that the Women's Preventive Services Initiative has kicked off its 2022 year. They are meeting currently to review diabetes, during pregnancy and postpartum to update those guidelines for this year. The committee has been meeting to deliberate on the evidence reviews. We also have a rolling-open period for individuals to submit recommendations for consideration for other guidelines to be considered on different preventive health services and screenings that can be provided.

That's all I've got for now. I'll stop. Doctor Warren, if you want to give an update on formula, that would be helpful.

JACOB WARREN: Thank you, Lee. And the timing is perfect. In about five minutes, I've got to hop on a formula call. So, as many of you

have been seeing for a while now, there are conversations happening around the shortages of infant formula. There had been some shortages throughout the pandemic due to supply chain issues, and then with the closure of one plant in North America really exacerbating that across a number of types of formula, particularly for specialty and metabolic formulas. There has been a cross-government group that has been coming together very regularly. There are actually multiple groups that are meeting on this. The one we're a part of is an across-government group that's got engagement from the White House, multiple parts of HHS, the Office of the Secretary, FDA, the Assistant Secretary for Preparedness and Response, as well as us here at HRSA and certainly our colleagues at USDA who were involved with the Special Supplemental Nutrition Program for Women, Infants and Children, or WIC.

A number of things you likely have seen in the media, the effort to bring formula into the United States, Operation Fly Formula -- and I will

paste a link to the latest release. Those shipments or flights continue bringing in formula that has been vetted through FDA from other countries that will then be available through a variety of outlets in the United States.

There's also been the invoking of the Defense Production Act to make sure there aren't any barriers to be able to get the supplies that are needed for formula manufacture in the United States.

A few very specific things that we have been involved in helping with, the department launched a website that has information for families as well as providers, and I will put that link in the chat. That has been updated several times, and we've been involved through MCHB with that.

We've also been involved in connecting with our grantees. So, as you all know, we've got a number of grantees in a variety of settings, everything from state block grants, who are hearing from their partners, from family

organizations, from providers, from community service organizations with insight, but we also fund things like the Regional Genetics Networks. And those grantees work very closely with families who may have infants or children or adolescents who may need those specialty and metabolic formulas. So, we've been gathering that information and making sure that's relayed so if there are particular challenges that we're sharing that information back up.

We did some listening sessions at the AMCHP Conference. Laura Kavanagh our deputy and I always meet with all the states at the AMCHP Conference. We have continued to do that even virtually to be able to understand what are the challenges. They're not the same across all the states. And, for example, we were particularly interested in hearing from the freely associated states and territories as well, and understanding are there differences there. So, those sessions were helpful.

We and MCHB have issued some messaging

a few times now for our grantees with information that they can share with families, also information for providers, particularly providers who need to access specialty formulas and resources to do that directly from manufacturers.

And then, lastly, I'll just say we're participating in a number of public-facing educational webinars. So, the Assistant Secretary Admiral Levine did one for the Moms Rising Group last week. We're participating in one tomorrow for a parent advocacy organization, on Thursday for the National Association of Social Workers, and then on Friday with the Tribal Child Welfare Group. So, really trying to make sure we're engaging with partners across the country on this issue.

Certainly, if you all have insights or things that you're hearing, please share those up through the committee staff, and we will make sure that gets relayed.

Thank you, Lee.

LEE WILSON: Thank you, Doctor Warren.

Magda, I wanted to let you know that Anne Leitch will be dropping in if she hasn't yet to the box, the response to your question about the recipients of the awards.

I also see that our friends from CDC, from OMH -- I'm not sure if NIH is on the line as well but wanted to give them an opportunity.

Charlan, welcome to this committee meeting. Charlan Kroelinger at CDC is now the representative of the Division of Reproductive Health, big shoes to fill after Wanda Barfield's departure, but Charlan is up to the task. So, I'll let Charlan and any other agency representatives provide their updates. Thank you.

CHARLAN KROELINGER: Thanks so much, Lee. And good morning, good afternoon again to folks. I'd like to thank the Chair of the Committee Doctor Ehlinger, for requesting this update to provide additional information on activities relevant to the presentations and panels provided today and tomorrow.

So, I'd like to start with some updates

from the Division of Reproductive Health at CDC. In partnership with the Office of Minority Health, CDC's Division of Reproductive Health is developing a segment of the Hear Her Campaign specifically focused on reaching and serving American Indian and Alaska Native women and their communities. In January of this year, the National Indian Health Board hosted a discussion session on Hear Her messaging. The meeting was attended by over 300 tribal health practitioners, tribal health directors and others who serve American Indian and Alaska Native pregnant and postpartum women. The feedback provided was critical for Hear Her messaging that's currently in production and will be released later this year.

In fiscal year 2021, CDC funded 30 recipients through the Erase Maternal Mortality Program supporting Maternal Mortality Review Committees or MMRCs work in 31 states. By the end of September 2022, with the fiscal year 2022 omnibus appropriation, CDC anticipates adding

approximately eight additional state MMRCs. In addition, with the same appropriation, the CDC anticipates a new effort to directly fund tribal nations and regional tribally designated organizations representing over 100 tribes for engaging informative work to define a tribally led MMRC approach. CDC is also working with the National Indian Health Board to support implementation of a tribally led MMRC. As of December 2021, 45 states and three cities with active MMRCs in the US are using the Maternal Mortality Review Information Application or MMRIA to guide their data collection and committee decisions with almost 6,000 review deaths entered into the MMRIA system to date.

For sudden unexpected infant death or SUID and sudden death in the young that we just heard the panel speak about, in fiscal year 2021, the Division of Reproductive Health supported technical assistance to Navajo Nation for a SUID SDY Child Death Review CDC-supported provision of technical assistance on the Child Death Review

process and for the Case Registry Data Collection System based on the National Fatality Review Case Reporting System we just discussed. CDC partnered with Child Death Review programs that span Navajo Nation to create a roadmap of cases from death to review to case completion and prevention. Coordinating these activities included engaging law enforcement agencies and other stakeholders involved in creating the primary data sources necessary for a complete review of SUID and SDY cases. In November of 2021, CDC provided additional support to expand capacity-building and technical assistance efforts to enhance the review of child deaths with 35 death investigators from Navajo Nation trained in infant death scene investigation. Participants responded positively to the training, and the Navajo Nation requested additional trainings for their investigators in the future.

With the FY22 omnibus appropriation through a partnership cooperative agreement, CDC plans to expand support to 10 to 15 jurisdictions

who are not currently funded through the SUID SDY Case Registry. CDC is also increasing support to development of trainings and best practice guides for death investigation and other materials for strengthening systems. Additional funds will be used for the system enhancements of the case reporting system designed to support case registry awardees and others conducting surveillance.

CDC will also issue a new notice of funding opportunity in fiscal year 2023 for a cooperative agreement to expand the case registry by increasing the number of awardee jurisdictions receiving support for SUID SDY surveillance programs. Additionally, case registry applicants will be able to apply for a new component of the cooperative agreement in which awardees will develop and implement data informed SUID prevention strategies that address the drivers of disparities in disproportionately impacted communities.

Finally, for CDC surveillance, five Pregnancy Risk Assessment Monitoring System or

PRAMS sites completed activities to support tribes in the last nine months, including, for example, Montana PRAMS that updated a data dashboard to include American Indian and Alaska Native population estimates for a number of the indicators. Montana PRAMS also held a steering committee meeting, which included updates, discussions and decisions on an American Indian Alaska Native sampling plan for the survey year 2022, American Indian and Alaska Native planned outreach activities and a phone prompt experiment, which included American Indian and Alaska Native subgroup analyses, and, finally, a summary of a project from last summer that looked at driving factors of American Indian and Alaska Native response rates particularly related to geography.

The CDC's Division of Reproductive Health continues to provide support for maternal health activities among American Indian and Alaska Native populations and plans to continue to build capacity and improve partnerships among tribes, tribal organizations, and tribal epidemiology

centers. Thank you so much for the time to provide this update.

LEE WILSON: Thank you, Charlan. That was very, very helpful. I appreciate it.

Does anyone have any questions for Charlan?

CHAIRMAN EHLINGER: I did really appreciate the update. That was very, very helpful. There's some really good activities going on. So, thanks.

LEE WILSON: I'm not sure whether IHS, NIH -- I know that we've got -- I'm sorry. I'm not sure whether NIH or FDA are interested or OMH are interested in making a presentation. I'm holding off on IHS because I know that we're going to have them talking to us after the break. So, anyone from the other agencies?

CHAIRMAN EHLINGER: I'm also going to give another opportunity -- because after the IHS presentation, we will be having a longer discussion about that. So, if any of the other ex-officios, you know, want to be thinking about

what kind of role they're playing related to American Indian and Alaska Native communities related to some of these issues, that would be also another opportunity for them to share whatever they can at that point in time.

LEE WILSON: All right. Doctor Ehlinger, I think that calls that --

CHAIRMAN EHLINGER: All right. Well, I just have one -- and I know Doctor Warren, Michael Warren has gone, but I remember back in the Eighties when the USDA, to try to save money on formula and to extend, you know, started contracting with, you know, a sole source for formula, it allowed the feds to save a lot of money and expand WIC. But the world has changed dramatically since then, and obviously the formula issue, because of the limited number of manufacturers that WIC is contracting with -- I'm just wondering if there is -- and with COVID, talking about the extent of lines, supply lines, and all of those things changing, if there's some conversation going on about kind of re-looking at

how the feds interact with the formula manufacturers. And I would just -- you know, I was going to raise that with Doctor Warren, but I think now's the time to do some of that thinking because the world is a little different now than it was in 1980, '85 when this was first put into place.

LEE WILSON: Doctor Warren is not on the line, but I do know that there are discussions around supply chain issues and sort of dependency on one specific or two specifics, a small number of manufacturers or providers of products that are considered essential. I'm not sure the degree to which there is a specific team with charge to come up with a solution to this particular problem. Generally, FDA or other organizations that are charged with this sort of responsibility try to develop a framework that would be used as a standard for making those determinations across the board so that it's not piecemeal. I would encourage the committee, if you have any recommendations or suggestions on this particular

issue and factors that should be considered in the importance of this issue for the population that you've been charged to address or speak to, that if you have recommendations to bring them up and articulate them, and we would be happy to forward them to the secretary as you see fit.

CHAIRMAN EHLINGER: Thanks. Any questions from members for Lee related to MCHB? Magda?

MAGDA PECK: Actually, it's a question that goes to Charlan at CDC, and it's a segue into the conversation after the break and also Doctor Warren's comment about listening to and having conversations with the National Indian Health Board. One of the things that I think will be helpful for us in SACIMM is to have some just brief introduction to what is the Indian Health Board, how is it different from the Indian Health Service. There's a landscape of partnerships, organizations, and vestments, and so either now or when we move into the session and we talk about the Indian Health Service, it'll be just very

helpful to know who do you talk to, how our voice is heard, who represents whom, what is sovereign. And I just would appreciate a 30-second refresher on that so there's context.

LEE WILSON: We will do what we can to have that covered.

CHAIRMAN EHLINGER: All right. Seeing no other hands up, let's take a break. I can certainly -- I need a break right now, so I hope others do too. So, let's come back at 1:45 p.m. Eastern Daylight Time.

BREAK

(A recess was taken.)

CHAIRMAN EHLINGER: Welcome back to everyone. I hope you were able to take advantage of a, here in the Midwest, a perfectly timed lunch break, or for those on the east coast sort of a late lunch break, or those in the west coast an early lunch break. I hope you had enough time for whatever you needed to do during that time. So, welcome back. It was a great first opening

session, sessions.

I know we've got a couple of new members who have joined us for this afternoon, and I would like to have them take some time to -- like I did with everybody else, take a minute, as I mentioned in my e-mail last night, to introduce yourself with a what-it-will-take-to fill-in-the-blank question.

So, Marie Ramas, welcome. Introduce yourself to the rest of the group.

MARIE RAMAS: Hello. My name is Marie Ramas. My pronouns are she, her, hers. I am a family physician and current President New Hampshire Academy of Family Physicians, a mother and a wife, and a passionate advocate for health equity and all spaces thereof. ‘

There was a question, I think, Ed, you asked in the e-mail, what's one thing that I would like for -- that we could add to make healthcare and the healthcare delivery better. I think, if we could as a system recognize the humanity of each person in our communities that we serve, we

would go a very long way recognizing the humanity in one another. So, I will leave it at that.

CHAIRMAN EHLINGER: Excellent, excellent, excellent. And ShaRhonda, ShaRhonda Thompson, glad you're with us this afternoon.

SHARHONDA THOMPSON: Hello. How's everyone doing today? My name is ShaRhonda Thompson. My pronouns are she and her, and I am a community advocate. I am here as the voice of the people to see what we can do. And what I want, what I would love to see is an elimination of all the racial disparities in healthcare. That would be my perfect ideal world if we can eliminate those.

CHAIRMAN EHLINGER: So, then the question was what would it take to do that.

SHARHONDA THOMPSON: Oh, what would it take?

CHAIRMAN EHLINGER: It doesn't have to be expansive. One little step.

SHARHONDA THOMPSON: The first step would be for me, I think, training starting in

college to look at people as people as a whole and not as a race, not going into it thinking -- because I know there are some things that are already in place that aren't factual, like, you know, African Americans have a high tolerance in pain; so if they are complaining about pain, oh, it's okay, they can just deal with it. Well, that's not true. That's not true. So, if we can eliminate those starting off while they're in school, maybe listening to real-life stories while they're still in school and still training and listening to community while they're still training, it could possibly help once they're out and they're doctors on their own.

CHAIRMAN EHLINGER: Excellent. Excellent. Good. Well, I'm glad you're here, and I hope we hear your voice during our conversations along with everybody else's voice. It's important to have everybody contribute.

INDIAN HEALTH SERVICE

CHAIRMAN EHLINGER: This afternoon,

we're going to basically have two things. One, we're going to be focusing on the Indian Health Service, and in the latter part of the afternoon we're going to focus on the recommendations that have been sent to everybody. But it was obvious that if you're going to be talking about the health of First Nations mothers and infants, we need to pay attention to what's going on with the Indian Health Service. And I think you all know that we've been having some difficulty getting information from the Indian Health Service over the last several months, so we didn't have the right kind of information to really make some good basic recommendations related to the Indian Health Service. Fortunately, in the last three months, the Indian Health Services has appointed an MCH consultant, and that person is Tina Pattara-Lau, and she's going to be joining us. And I had a conversation with her week or so ago.

Hello, Tina. Glad you're here.

And, like I said, she's been in this position for three months. She'll explain a

little bit more about how she's been working with the Indian Health Service in a clinical capacity for a much longer period of time. But she's assured us that she really is interested in working with this committee over the summer to come up with some -- getting more of the questions answered that we have, and helping us, working with us as we develop some recommendations related to the Indian Health Service, since it is an important and critical part, but certainly not the only part of what we need to do with improving the health of Indigenous mothers and babies. So, what we're going to do is we're going to, you know, spend some time finding out from Doctor Pattara-Lau what she's doing, some of her perspectives, what she can share with us. We'll have some time for question and answers. And then following that we're going to just open it up for some general conversation, you know, with our federal partners and with members of this committee, about how we want to -- what questions do we need, what other additional information do we have, what do we want

to know about what's going on. So, we will have -- so be formulating your questions and the things that you need to know.

So, first, let's turn it over to Doctor Pattara-Lau. Thank you for being with us, and I look forward to your comments.

TINA PATTARA-LAU: Thank you, Ed. Good morning. Good afternoon. And thank you to Doctor Ehlinger and Palacios and your committee for inviting me to introduce myself and be present today. I also want to recognize two of our senior leadership who are on with us, Doctor Loretta Christiansen our Chief Medical Officer and Ms. Elizabeth Carr who is our Senior Advisor to the Director for IHS. So, thank you for your presence as well.

My name is Tina Pattara-Lau. I'm the new Maternal Child Health Consultant for the Indian Health Service. I'm an OB-GYN. I've been practicing at Phoenix Indian Medical Center or PIMC and flying to both Parker and Peach Springs here in Arizona for the last seven years.

Currently, I'm sitting on tribal land. I'm also a wife and a mother of two very active boys. I commissioned into the Public Health Service in 2007, completed medical school at the Uniformed Service University. I did my OB-GYN training at the Naval Hospital of San Diego before joining the IHS.

As I previously shared, my first year as an intern, I was actually trained by midwives including a low-intervention birth and centering models. I'm glad to see this model in collaborative practice as reflected in the IHS as well. I'm honored to serve and represent the many Native people I've cared for and worked alongside. I speak from my experience as an OB-GYN in both urban IHS hospitals and rural clinics. It was actually a month ago I was caring for patients on a daily basis. And, as one patient shared with me on my last week, You're the only provider I have seen consistently through the highs and the lows of my pregnancies. We will let you go as long as you go forward and speak our truth.

I'm very familiar with the challenges facing IHS facilities and similar rural or underserved communities. I appreciate that the needs of our patients are complex, reflecting both traumatic and resilient health histories. Providing care in IHS is not as simple as writing a prescription or performing a surgery. It is earning mutual trust so that I may learn about personal, family history, traditions, access to clean water, shelter, food, health literacy, racism, discrimination, historical trauma, mental health, addiction, and intimate partner violence. These and other social determinants of health affect access to quality healthcare across generations. To provide this comprehensive level of care takes a multidisciplinary team approach including community health outreach and cultural support. My hope is that our team can grow the MCH program to provide a standard readily accessible set of resources in collaboration with healthcare and tribal partners to help our site succeed.

There are many stories of dedicated Native and Native-ally individuals who choose to serve in IHS. I intend to speak for their needs and highlight their best practices. Looking forward, we share a common goal. We want to utilize the resources of the government for all Native patients, those who receive care in the IHS tribal facilities or the private sector.

I appreciate the committee's trust and patience, as I learn this new role and the national landscape. I'm here to listen, learn and work with you to provide what you need to make well-informed recommendations, and thank you for advocating for our Native patients.

Briefly, Doctors Ehlinger and Palacios did brief me last week on the status of the committee including your time-sensitive recommendations to the secretary. I understand I may not have all the information you may need in the short-time I've been in this role, and I've asked our senior leadership as well as to be present and hopefully fill in any gaps.

Doctor Ehlinger, I did compile some comments on the recommendations that I will pass on to you after this session. Please let me know if it is most helpful for me to proceed with a brief overview, or if there are any comments at this time.

CHAIRMAN EHLINGER: Why don't you start with a brief overview, and then, when you're done, I was wondering if we could -- if the organizers of this could pin you and Doctor Christiansen and Elizabeth Carr on the screen so we could actually have a conversation with the three of you so that, you know, the questions could get answered by you or the other members of your senior leadership team. But why don't you go ahead with your comments first.

TINA PATTARA-LAU: Of course. So, I wanted to start just with a very brief overview of IHS as well as the structure before I take steps into what we know about our maternal care delivery model and our best practices as well as areas that we could use some help and improvement.

So, first, the IHS is an agency in the US Department of Health and Human Services. It's responsible for providing federal health services to American Indian and Alaska Natives based on treaty obligations and rights established circa 1955 and funded via appropriations from Congress. Our mission is to raise the physical, mental, and social and spiritual health of Native Americans to the highest level. We service a population of approximately 2.5 million of the nation's 5.2 million Native Americans you belong to 574 federally recognized tribes in 37 states.

The structure of the IHS is divided into headquarters as well as 12 service units that I'll talk some more about, but healthcare -- the headquarters level is responsible for setting policy, ensuring delivery of quality comprehensive health services, advocating for the needs and concerns of American Indians, Alaska Natives. The 12 area offices then is responsible for distributing funds to the facilities, monitoring operations, providing guidance, and technical

assistance.

Within the system, there are really three healthcare delivery systems. And I again do ask Doctor Christiansen or Ms. Carr to chime in to help me explain further for the committee. But the first is the federal system, which is where I come from. It's funded by appropriations from Congress, consists of 26 hospitals, which we'll talk about as we move towards our delivery sites, and range in size from four to 133 beds. Average age of facilities is about 36 years. The second healthcare delivery system is the Tribal Health Programs or 638 Programs, as you will hear. They're operated by tribes or tribal organizations who assume full responsibility for healthcare, formally offered by the federal government per the Indian Self Determination Education Assistance Act in 1975, and these tribes operate with full sovereignty. It consists of 19 hospitals. And I believe there was a question from Magda on prior discussion regarding what is the role of the National Indian Health Board. And so, they

actually represent tribal governments, both self-governing and those receiving care through IHS. They provide advocacy, policy. They actually have an advice to Congress, IHS and other federal agencies. The third healthcare delivery system is the Urban Indian Health Centers established around 1976. It's estimated approximately 78 percent of Native Americans live in urban areas. IHS then enters into limited competitive contracts and grants with these 41 urban center nonprofit organizations to provide healthcare services. And the programs themselves define their scope of services based on the needs of their community. So, each urban health center will be unique in that sense.

Another comment I wanted to make, as of 2019 the total number of IHS employees -- I know this was one of the committee's questions -- was around 15,000, approximately 2,300 nurses, 770 physicians, 800 pharmacists, 270 dentists. And we have a rough estimate that approximately 70 percent of our workforce is Native American.

I mentioned the 12 IHS areas previously. So, seven of those areas do provide planned birth services. The volume, of course, will vary by the site, upwards of 50 to about 1,500 births annually. Nine of those sites are federal, 13 are tribal.

Some data. Now, this comes from CDC, but we have discussed and I've heard on this committee before American Indian, Native American and Alaskan Native, I apologize, women are two to four times more likely to suffer pregnancy-related mortality than their white non-Hispanic counterparts, and they're twice as likely to report late prenatal care or no prenatal care, which is approximately 12 percent of births. Infant mortality is 26 percent higher than the national rate, and they are three times more likely than the overall population to have diabetes.

When there's significant trauma that's affected a community, we see worse health outcomes over generations beyond those events. We see now

in our Native youth, they are inheriting this trauma, but they may not have the same cultural resources and teaching for healing that their elders might, and that is a goal of our urban health centers.

In the IHS we have tried to keep track of our own birth data using a combination of information from annual facility reports and newborn admissions and the National Vital Statistics Report. So, this is very raw estimates that we use to help understand what our numbers look like. I want to add that the National Vital Statistics Report uses a single race identifier, which we estimate may undercount Native births by 25 percent or more. So, using those numbers, approximately less than 20 percent of Native births occur at IHS and tribal facilities across the US. Less than 10 percent of those births occur at IHS federal facilities. And we know that Native births occur in all 50 states, including the District of Columbia, and only seven of those states have IHS federal or tribal facilities. So,

we would advocate for a combined approach. To address health disparities, it is important to address all national health systems providing care to Native people. Systemic racism affects birthing safely nationally. Rural and urban health disparities affect rural people, including Indigenous people living in rural areas. We would also advocate that the National Vital Statistics address this. Policy implications of electing a single race versus a multiple race identifier and provide ready access to multiple races identified data. As mentioned in one of the prior discussions, there are also Tribal Epicenters and Tribal PRAMS or Pregnancy Risk Assessment Monitoring Systems that also have data on pregnancies.

I'll continue now just to highlight some of IHS best practices both from my time as a provider -- and this is not inclusive, but we have -- the CMO has advocated to have bundles as verified by ACOG and promoted across IHS hospitals that perform planned births. We have achieved

Baby Friendly Hospital designation at all facilities that perform planned births, and this helps promote breastfeeding as well as education for the mothers. We do have a midwifery collaborative practice. I believe there was a question in the chat about how many midwives are employed. As of 2019, that number is about 84 positions across five of the IHS sites. And it really is a collaborative practice. I speak as a physician who, you know, works with the midwife to ultimately offer the best care model for the patient. And in traditional cultural practice, the woman is usually attended to by multiple family members, providers as well. And so, I can allow a midwife -- not allow, but I can rest assured that a midwife can work in our practice together and provide a patient with the care that she is most comfortable with, especially for routine low-risk birthing situations. And if I ever needed assistance, some midwives are even trained to first assist and can go back to the operating room with me, thereby allowing me and

the midwife to work at the highest levels of our education.

MMRCs, which I know that the committee has discussed, do often include IHS and tribal clinicians and tribal members. We would again advocate to continue to recruit Native voices for this initiative. We did start a pilot project for obstetric readiness in the emergency room to help address -- basically to address obstetric emergencies that might present in a rural setting. So, we formed a multidisciplinary team, including our obstetric nurses, pediatricians, ER providers, and did simulation training using ACOG's model on precipitous delivery, postpartum hemorrhage, and hypertensive emergency for over 100 providers over at PIMC. This helped increase their confidence levels and familiarity with the equipment resulting in safe triage, stabilization, transfer of over 200 patients.

In addition, we've incorporated during COVID a telehealth model into our prenatal care practices. This year we actually rolled out a

trauma-informed care training to be taken by all of our staff.

And, finally, another program that was near to us at PIMC was the White Feather Program for those patients who had a fetal loss, were seen on labor and delivery. This was started by one of our Native elders who is an obstetric nurse, and she actually put together a very culturally sensitive program on how to address that loss with the family, but then also what practices and questions should be in place.

Finally, just speaking to the MCH program, I understand there are many areas of need, and I just in my mind can separate them into the acute and the long term. The acute needs would, of course, be things like staffing and facilities. And so, that's something that, I think, most of the frontline staff on the ground would benefit from. Long term, I hope to grow the MCH program with the goal of being the support for patients, staff, and the sites to grow and expand on the obstetric readiness and ER program for

rural areas, not just in IHS, but this does affect other departments including, for example, our partners at the VA. The VA also has a model using maternity care coordinators, or one or two nurses for each division or site that would help -- because again patients are transferred out throughout their pregnancy, or perhaps, move to a higher level of care. These coordinators would help them follow pregnant women during the pregnancy to ensure they're accessing the resources they need to stay healthy, but then also capturing any significant social determinants of health and getting those resources on board and the high-risk medical conditions, diabetes, hypertension, and then, most importantly, postpartum making sure that they have access to the care they need, potentially home visits to take a look at the environment that the family is returning to, the sleeping arrangements as you did mention in your previous talks as well.

And lastly, really leveraging our academic partnerships. We do have a need in our

recruitment and retention for staff, there is, as you know, in the United States a wave of an advocacy for provider wellness. I speak very strongly to that because it does affect many providers, not just in IHS, but in other communities. And so, we do have challenges with our recruitment and retention that we could continue to improve. We do have a model through the Uniformed Service University of which I'm an alumni is now sponsoring five IHS students per year who will then enter a commitment to serve us in IHS after graduation from residency.

So, in addition to that, I realize the need for being able to collect and hopefully provide more concrete data to help guide not only our initiatives, but I do believe that we can then use this data to help inform our decisions and our policies to help make our own best practice recommendations as well on behalf of our patients.

Briefly, my last comment, Doctor Ehlinger, unless you have additional topics, was just to touch on the ACOG contract, if that's

okay. So, this is a partnership that has existed between IHS and ACOG since 1970 for ACOG then to provide professional support to colleagues providing women's healthcare to American Indian and Alaska Native populations and to serve as a liaison and a source of consultation. This relationship, as a provider in the field, has been very mutually beneficial from my point of view. ACOG has been able to do several things that have, I think, really elevated the care that we deliver. First, they do site visits for quality benchmarking on which they tour the facilities, talk to our staff, interview tribal members, do HIPAA-compliant chart reviews, look at policies, facilities and then, you know, evaluate these, and make recommendations based on ACOG and IHS standards. These reports are peer reviewed and given to the site's, local leaders, and the director of IHS as a summary of best practices and findings.

Second, they do provide an ACOG-IHS postgraduate course every one or two years that

focuses on needs specific to the Native population, mental health, substance use disorder, intimate partner violence, but also trainings which are required by our sites. Indigenous Women's Health Conference takes place every two years. Last one was virtually in 2022 also focusing on cultural issues, mental health, trauma, depression. There is a focus, as I mentioned, as well on maternity care in rural hospitals, which I am also very passionate about.

Lastly, as I mentioned, the bundle implementation and then implementing screenings for cervical cancer, diabetes, opioid use, they are fierce patient advocates as well at IHS. One of their recommendations back in 2020 was actually to fill the position that I'm currently in, which is to have an IHS maternal health consultant to help be that point person with other agencies and to be the subject matter expert here for IHS. So, I'm quite honored to fill that role.

Those were the points that I had. I would defer to Doctor Christiansen, Ms. Carr, if

you have anything else to add, and, of course, to the committee if you have questions for me. And thank you again for your time.

CHAIRMAN EHLINGER: Thank you, Doctor Pattara-Lou. And before we open up for questions, I do wonder if Doctor Christiansen or Ms. Carr would have some comments that they could add, and then we can open up for general questions if they have something that they would like to add to what you already presented.

LORETTA CHRISTIANSEN: Yeah. This is Doctor Christiansen. Thank you so much. Thank you, Doctor Pattara-Lau. Just a few little additions. She did a wonderful job in that summary. We do have some -- as you well know, there are multiple maternal child health programs going along through the White House through HHS and through multiple other agencies. So, we've had the chance to really look at what we do in our agency that I think supports everything that we provide for our moms and our newborns. And one of the things we're heavily involved in with the

Federal Hypertension Group is monitoring, self-monitoring blood pressure in our pregnant persons. So, we have deployed over 800 blood pressure monitors out into the field into the pilot sites to have these moms or pregnant persons monitor their blood pressure, as we know self-monitoring is actually more accurate and more beneficial to the patient. So, that is something we've done to look at and, you know, prevent any preeclampsia or any issues like that very early.

I think when you look at our morbidity and mortality, when we have broken it down, certainly all of us on this call want very little or no morbidity or mortality. But when we really look what we're doing, it really wasn't any medical failures within our system with our pregnant persons. It was the social issues. It was the homelessness. It was the lack of social services. It was a lack of support, childcare, other things that kept people from getting the care that they should have gotten. So when we really broke it down, I mean, that's still very

serious to us that this has to be mitigated, but we were happy to see that on the medical side of things we were actually operating very well and we did not have a lot of morbidity and mortality that we could go back and say it was the way we provide OB-GYN care.

However, we do have to look at that social milieu, how do we get all of our moms into prenatal care, how do we get them all the way through prenatal care. And, you know, it is quite challenging in rural areas in Indian Country, because there is that right to come to appointments or take that telehealth call or not. And we are trying to really educate our moms and our moms to be on how important that is for us to always be able to monitor them so we could step in very early and avoid morbidities and have a good birth.

We also cannot -- we'd be remiss in not looking at the health of our pregnant persons before pregnancy. We all know that the health outcomes and lifestyles of our patients have a

great impact on how healthy the pregnancy is going to be and how healthy the baby will be as well. So, we can't just start when they're pregnant. We know we have to start before that, improving food insecurity, improving lifestyle, decreasing obesity, looking for early signs of diabetes, before we address it during pregnancy. So, that is all very important that we're looking at this whole lifestyle span.

The other thing I wanted to add to make sure that we're all very clear on this, we work very well with our tribal communities in urban sites. However, them being sovereign nations, they do not have to share data with us. Some will share data because we work together, which is great. And we'd love to look at all our data for Indigenous populations very closely. But these are all dependent -- each tribe owns its own data. So, in collaborative manners we can actually try to continue to work with them for more robust data sets. We can certainly do our own Indian Health Service data, and we're happy to do that because

we want to measure where we are. But we cannot provide compacted or contracted data unless the tribe consents to that. We are doing -- we're working very hard at the headquarters level to make this more robust along our trauma epidemiology centers. We're creating more data sets for them. We are increasing the amount of data they can request. And I'm hopeful, I'm hopeful to this group, we'll get more of the data that can really give us a good picture of what's going out across Indian Country so that we can have a more robust discussion about how we're managing maternal health.

So, I just wanted you to know that. And a lot of the -- I know there was a question about NIHB earlier. These are all independent tribal organizations that work to put forth the policies and the needs of our tribal communities. They are independent. We do get invited to their meetings. We do report. We do talk. But they are definitely independent tribal organizations as well. And they're typically policy type of

services that they provide to the tribal communities. So, I just wanted to maybe fix a little bit of that information, so you understand the milieu in which we work in. And, you know, I'm certainly happy to answer any other specific questions. Thank you so much.

CHAIRMAN EHLINGER: Doctor Christiansen, thank you very much. You did mention one thing that I think would be helpful to clarify, contract and compact relationships. So, could you explain the difference between contract and compact and other hospital care, and also your relationship with Medicaid?

LORETTA CHRISTIANSEN: Okay. Well, first of all, under the self-governance type of contracts, there is a contract which we call Title I where they will take specific programs. So, they could, say, just take behavioral health or they could just take the public health nursing and they would manage that. They would get all the money and resources to manage that particular service. So, we have a lot of those contracts,

Title I contracts across the country. Most of the hospital stuff won't be in there. It's hard to break the hospitals apart. Some do, but it's more your outpatient services, behavioral health and social services and things like that. And so, they can contract for those specific services.

Where we go to our Title V compacts, they take the whole thing. They take -- they come in and say we want this service unit; we think we can manage it. They go through the whole process. It's vetted, it's looked at, it goes through the thing and then we say here's the keys. They take the building, the staffing, the money to support those programs, plus some other calculations that are fairly complex, to make sure that we're handing over everything they need to be successful. It is our hope and our goal to make them successful as self-governing entities. So, for example, if you took over X hospital, I would take everything, all the services including L and D, you know, surgery if it was there, the emergency department, everything, and I would

begin running that hospital now as a tribal organization.

And they're set up in different ways, by the way. But that's basically the difference. One is taking single programs, and the other is taking all of the programs at a specific site.

And I know you had one more question. I'm sorry.

CHAIRMAN EHLINGER: How the Indian Health Service relates to Medicaid, because a lot of funding for maternal and child health comes out of Medicaid, and I'm assuming with the Affordable Care Act with no copays and special set-asides for American Indians and Alaska Natives, explain how that works.

LORETTA CHRISTIANSEN: Yes, of course. Our funding is a little bit different. We do participate with, of course, Medicaid and Medicare, and we have a good relationship with CMS overall. Quite frankly, in pregnant persons, almost the vast majority are qualified for Medicaid and will be enrolled immediately, so they

will have that in place when they are going through their pregnancy. And then we have well over 90 percent, 90 to 95 percent of our pediatric patients or the newborns on up will also be in Medicaid, and they take -- you know, get great support from those programs. As you well know, the Indian Health Service, we're self-funded as far as we're appropriated for the work that we do, and our rates are determined differently by CMS. But if they have third party like Medicaid, we, of course submit that bill to Medicaid, we get our payment, actually, rather quickly. So, they're very good with us, their turnaround time. And then for those few percent that might not qualify for Medicaid, the Indian Health Service will cover all of those costs. So, there is no time that a pregnant person should not be supported with healthcare services. Even if they're sent to a facility 100 or 200 miles away, we use what we call our purchase-referred care funding, which we are again appropriated through Congress for every year a certain amount and the certain amount goes

to each facility. And I will refer that patient out, and sign that off to them. They get full care wherever they go, whether it's high-risk pregnancy, anticipated difficult delivery, or neonatal care for the baby should there be any issues, it is all covered by IHS funding through that program.

CHAIRMAN EHLINGER: All right. Thank you. I've got lots of questions, but I want to ask other committee members if they have some questions. Doctor Ramas?

MARIE RAMAS: Thank you. Thank you for the presentation. I have two specific questions, one I put in the chat. Doctor Pattara-Lau, there was mention of incorporation of certified midwives with maternity care. Can you share a little bit of how family physicians are incorporated within maternity care structure and framework as well, considering they also help support, particularly in rural health management?

And then my second question was, what has been your level of exposure or experience in

supporting those who identify as two-spirited in their gender identity, and how has that been incorporated within gender-affirming care in this light.

TINA PATTARA-LAU: Thank you for your questions, Doctor Ramas. The first is that yes, we do have a number of midwives who do support and work in collaboration with us. I personally have training practice in working with family medicine specialists, including those who are fellowship trained in performing C-sections and find their expertise and help to be very valuable. And so, I do have -- I do have experience in training. I have not at PIMC specifically. I'm hoping that Doctor Christiansen or Ms. Carr can also speak to that as well.

And then, in regard to, your second question with individuals identifying as two-spirit, I strongly believe that our verbiage is very important as well. And so, I do apologize. We should refer to all pregnant individuals as pregnant persons, and I think that's my first step

personally is starting there with the language that I use. And in my practice, when I do speak to a patient, I always say I ask and I never assume, what is your gender identity, what pronouns would you like me to use, what are your relationships with male, female, or both. And I do believe that we start by changing our awareness, we change our language and then, of course, using that education across our division. For example, Rick Haverkate is an individual who I recently had the honor of listening to and is Director of HIV and Hepatitis Clinics, and he himself has been a fierce advocate for the community. And just listening to his talk helped educate me, so I'm hoping his webinars that he has coming up, especially for Pride Month, will continue to educate our population as well. Thank you for the questions.

LORETTA CHRISTIANSEN: If I can just jump in and, Doctor Ramas, to just build off that, we're very supportive of our of our LGBTQ two-spirit. It is a very strong force in IHS. We are

working on ways to support in many different ways. We are going to be beginning to ask those pertinent questions as part of the permanent record so that we can definitely address people appropriately and deal with them in a way that is sensitive and responsive to their needs. So, this is a priority for us, and it's something we all watch very carefully, and we try to educate constantly, because it is some change for some people, and we want to give them that opportunity to transition with us as we become so inclusive that it won't matter anymore, you know, so that it is just normal. So that is something that is actually very important to us and something we participate, again, in multiagency calls about how we do this, how do we support this along our way. We do have some clinics for our LGBTQ patients that is specific to their needs and addressing any kind of gender-affirming type of actions that should go forward, and we're very proud of those clinics, and we hope to expand more of them across the agency as we move forward.

CHAIRMAN EHLINGER: Thank you. Doctor Palacios?

JANELLE PALACIOS: Thank you, Doctor Pattara-Lau for joining us today and sharing. And then thank you for Elizabeth Carr and Loretta Christiansen for being here as well to help answer some additional questions. I just have two questions, one regarding funding and the second regarding data.

So, the first question I have regarding funding, I want the committee to really understand that, because of treaties that were made with Indigenous sovereign nations, the US government has a federal responsibility to provide services, and health service is one of those services. And, please, you know, speak a little bit about -- it was mentioned that the funding mechanism by which Indian Health Service is funded is through congressional appropriations, and what I understand is that varies year to year, which we heard. And can this funding be cut before it goes into Indian Health Service hands? Can this

funding be sequestered?

LORETTA CHRISTIANSEN: I'm sorry. Did you want to ask both questions, or do you want me to jump in?

JANELLE PALACIOS: So, for the first question for data is, like, you know, yes, for -- not data. For the funding. But can -- before the money is dispersed to Indian Health Service, is it possible for the funding to be cut, to be sequestered?

LORETTA CHRISTIANSEN: Anytime there's appropriated money, though, that has always been a possibility. What we're looking forward to is we have worked extremely hard to work towards mandatory funding, which would then not allow any sequestering of that funding because that is deleterious to us, quite frankly, and very stressful. So, we are working towards achieving the mandatory funding, which would then allow us to not ever be shut down and to not be sequestered, etcetera. So, this has been a long battle, as you probably know, and it's something

that we believe in very much. And so, we have crafted budgets that we feel -- and there's probably still not enough. I'm going to say that. But they're way more than we've ever gotten, and that is an encouraging step. I'm going to call it a step. We have asked for a lot more funding. We did get more funding this year, which we are sending out in whatever way it is indicated for such as the water access projects, the SFC huge amount of money is going out into the Indian Country to make sure everybody has running water and access to waste disposal and etcetera. So that is a huge step for us. Could the funding -- technically, yes. If it if it's appropriated funding, it could be cut. That's why we're asking for mandatory funding. It is very, very hard to plan ahead when you don't know what you're going to have, so that is extremely important to us as the Indian Health Service.

And I see Ms. Carr is on, so I'm going to kick it over to her for additional comments about that.

ELIZABETH CARR: Thank you, Doctor C. Yeah, I was just going to mention that. You know, this year the administration did propose a mandatory budget proposal for the first time in history, which is a really significant step forward. Of course, Congress has to act on that. And that's where our tribal organizations come into play. They do a lot of advocacy on behalf of Indian Country and IHS on the Hill because, as a federal agency, obviously we can't do that. And so that's the role that the National Indian Health Board, the National Council of Urban Indian Health, National Congress of American Indians, and other organizations such as those do on our behalf. So, I just wanted to kind of put that -- add that extra piece there, because I know that there was a question earlier about the role that NIHB plays in the space. So, thanks.

JANELLE PALACIOS: Thank you for those answers. So, I just want the committee to really understand that there is funding, it's appropriated by Congress and it can vary year to

year, and only most recently have we even come close to the actual funding that is needed. That's not really ever happened in our history through Indian Health Service that they haven't been adequately funded. And, as Doctor Lau shared with us, that, what was it, like -- the average age of the facilities are 30 plus years of age. So, we have an aging infrastructure that Indian Health Service is working with trying to deliver care in addition to this.

So, then this next question is related to data. What I heard also from Doctor Lau's presentation and from what Doctor Christiansen has said was that Native American populations in general can be a very complex population to serve because of all the different social milieu of health that have -- you know, without access to clean water or waste management, without access to electricity just as a baseline, in addition to facing institutional racism or systemic structural racism and poverty, incarceration, all those things. So, when we talk about hypertension in a

pregnant person and IHS being able to give out 800 blood pressure cuffs to monitor for hypertension, of course, the OB provider is not at fault for that person developing preeclampsia. What's at fault, is the social milieu that people are living like this, this historical legacy that people have inherited.

It sounds like definitely there is data that Doctor Christiansen was able to foreshadow a little bit by looking at maternal morbidity that it wasn't any kind of IHS service provision that was a factor for someone developing preeclampsia. It was the social milieu. So, with this data that was discussed just very briefly about, it seems to me that, despite the obstacles that are inherent in working with a small population of people, that there would be ways to communicate to this committee and to the general public that the needs of this population are very great, possibly greater than what we have even ever been told, and that there are possibly very wide regional differences. And are there any movements in

trying to be -- I mean I understand that you're working with National Vital Statistics and other avenues of trying to look at this small number data of data and possibly looking over periods of time collectively, aggregate, but how -- what are the mechanisms that would fast-track this data to be shared, or what kind of education could be given to tribal communities if consent is needed to aggregate information that would enable the committee here to understand just how grave the maternal morbidity and mortality really could be?

LORETTA CHRISTIANSEN: Yeah. Okay. Thank you for that question. I have two different answers that are both very important. Number one, what can we do? Well, one of the things we've worked very hard on since I arrived at headquarters is looking at the social determinants of health. It's very easy to say we have them because we have them all and we've had them all for a long time. So that doesn't help very much to me. So, I'm looking -- we're looking at it in a different way. How do we quantify, how do we

actually identify what we're dealing with and what is the relationship to what we're dealing with in SDOH that forms the risk that each person is under. So, our next step of our project -- we've defined a lot of SDOH. We have a great team that's working on this -- is we need to start asking those questions. So, our goal will be getting that into the electronic health record where all these SDOH domains will be questioned to each patient, it will be put in the system and apply a risk matrix to it to see who are our highest risk patients. So, to answer your question, if we have that data and we went back and we pulled all pregnant persons and we look at it, we could see the tiers of risk and where we might have missed something, where we will need to interject something ahead of time. But without data, without quantifiable data, it is very hard to make a plan to mitigate, as you as you alluded to. And in each one of our areas, the actual SDOH will be different for each area because some will have more transportation problems, some will have

increased food insecurity, some will -- you know, like you said, no running water, Alaska, part of Great Plains and Alaska, very prominent in those areas, and even some problems in California lately with water, maintaining water plants and such due to severe weather issues that have been going on there. So, that is a step that we can start to get some data out of to say this is what we're seeing, this is what's causing poor health, poor outcomes and impacting the lives of our American Indian and Alaska Native people. So, that is one big project that's rolling out that we will have in our system. And then we will have a heads up, this patient really needs to be tracked more than this patient. Although, they all deserve and need attention, this one is our high-risk patient. And we can certainly do that for our pregnant person population. And we have to do it before they're pregnant, as I said. We have to be looking at what's the health of the possible pregnancy ages that we have in our communities to make sure they're getting all that ahead of time, good food,

exercise, make sure they're not diabetic, make sure that they have healing food, etcetera like that. We can be very proactive in that. And that would be the goal is, how do we get a healthier population so when they are pregnant it is a more healthy and a better pregnancy. So, that's my first answer. So, that's one way we can gather data.

The second way I would look at gathering data is, we have some really excellent TECs, you know, epidemiology centers, and I don't think they have been fully actualized, if you will. I think by working with them, getting the data that they need to do some analysis in their own communities, because they know their communities very, very well, we have a chance to get some very robust data that we can address in each of those communities. So, I would highly encourage -- we are trying to even provide additional data and make it easier for them to request data that we have so that they can process all that data as an aggregate for that population.

But, you know, with it -- and, of course, I don't mind working with tribal organizations at all. I have worked very well with them in Navajo. We shared a lot of data. I think COVID changed a lot of things for us, and we saw what happened when we work together and shared data and mitigated and did things together. So, I am encouraged that working forward we can get that data you're talking about, but I do look to our TECs because I think they're a great asset and I would very much like to support their looking into our data and helping us plan and take care of our population better.

CHAIRMAN EHLINGER: I have a couple of questions. Has IHS evaluated the outcomes of compact tribes, contracted services, and Indian Health Service-run activities? Have you evaluated the effectiveness of those and found things that work and don't work better than others?

LORETTA CHRISTIANSEN: Well, I wouldn't say we evaluated them because, you know, as I said, they're tribal -- the tribal facilities are

very sovereign, and if they want to share their data, we're happy to work with them for sure. But I think that when we look at outcomes overall, we can get some lessons from them.

One of the things that the IHS has not been doing in the past, which we are working towards right now, is more participation in the maternal collaboratives. You know, we have certain -- I don't know if you all know. We have certain privacy data restrictions on us that we can't just say here's all our data. There is a process we have to go through that protects the personal health information of every one of our patients. Therefore, we have to -- you have to work through some of those challenges. And we have found some alternative pathways to use more aggregated data to participate because we want to hear best practices and we want to discuss our challenges. We want everyone at the table tribal, urban, state and IHS to learn from each other and to enhance maternal healthcare. So, we are looking at ways to do that. And we are highly now

encouraging everyone to participate in these collaboratives in a way that we -- say Navajo area shows up and says this is our data for Navajo area, this is where we have challenges, this is where we could do better. Same with Phoenix. Now, they can't go down to the minute data because it's identifiable and it would violate our privacy laws, but in an aggregate, we can have a good conversation and we can see what's going on. And then when we come back internally, our staff needs to get together with all of our partners and say, okay, this was my problem in this facility, this is what I saw, we had, you know, no prenatal care, how did you guys get your people into prenatal care so that we could help our pregnant persons. And so, I think that sharing of data and that group effort is going to be very key moving forward for maternal health. So, we look forward to working with our tribal and urban partners, and that would be the goal is for us all to work together. So, I think -- I think we have a good chance at that. And hopefully our partners in the

sovereign nations will work with us on this to make it better.

CHAIRMAN EHLINGER: Good. Thank you. Sticking with the evaluation question, has the ACOG contract with IHS been evaluated?

LORETTA CHRISTIANSEN: You know, I don't personally oversee that. It was in existence before I arrived at headquarters. So, I will have to follow up where we are with the status of that contract, and I'm happy to do that.

CHAIRMAN EHLINGER: Okay. Good. And then I understand the care for Alaska Natives is -- the organization of that is a bit different than it is for the American Indians in the other 49 states. Could you explain the difference and sort of the benefits or the pros and cons of the different kinds of approach?

LORETTA CHRISTIANSEN: Well, the Alaska area for us is all tribal, so we don't own any -- the facilities are all tribally run through their consortiums. So, they've developed oversight consortiums that do a really great job, actually,

really great job. And so, they have adapted the care to their population, their challenges, the way they have to do healthcare in Alaska, which is quite daunting, you know. And just to give you a visual, they were moving vaccine by dogsleds. You know, they do what they have to do to get things where they do, and we're using helicopters to drop vaccine in the bottom of the Grand Canyon to get to our clinics down there. We're extremely adaptive in Indian Country to get what needs to be done, and nobody knows better than those natives of Alaska to run their own programs. And they've developed these workstations and -- you know, they don't have formal clinics everywhere. It's not quite possible. But they have found other ways to train -- they had the chat program for a long time where they train their community health aides who are excellent. They have that for dental and behavioral health because those people in those communities are certified and educated to take care of their own communities, and they do a great job. So, they have developed their own health

system adaptive to their environment, adaptive to the personnel they have to do these jobs, and they've done it very well. So, they're great. Their consortiums are very, very good, and they're very great advocates for care. And we do love having them at the table because they contribute a great deal to the overall care of American Indians and Alaska Natives.

CHAIRMAN EHLINGER: Magda?

MAGDA PECK: I'd like to defer, if I could, for what's in the chat, because I think that Doctor Ramas had a comment that it would be helpful to elevate and also to hear from Shira Rutman. So, could we look at those two before I take my time? Because I don't want to miss -- they're very strong comments.

Doctor Ramas, is there anything you want to say about the comment you posted?

MARIE RAMAS: If it's referring to the last one, Magda. Thank you. I'm familiar that with particularly Medicare Advantage plans they're looking at incorporating community health workers

for their most at-risk patient populations, and that reminded me of the World Health Organization's mitigation strategy for maternal care in utilizing educational services for community members to help support maternal care and prevention services in a hyperlocal and a culturally appropriate way. And so, I was wondering if similar models are being taken into consideration. If not, I think it would behoove our committee to consider such community health worker models to implement, particularly in reducing maternal morbidity, mortality, and infant mortality. There's actually a -- and I put in a link from U Penn that shared a similar model for community health workers for particularly high-utilizing Medicaid populations, and the return on investment for paying for five community health workers to work for the highest risk population within this Medicaid pool was two and a half times fold, meaning that there was a spend of about 500,000 for these community health workers, which within a year's time rendered $2.5 million in cost

savings for these particular population group because of improvement of health. So, it's something, I think, not necessarily traditionally incentivized within our high-risk populations in the IHS for our NHSC medically underserved areas, but in thinking about creative models that we can implement in a hyperlocal manner, this could be another added recommendation.

MAGDA PECK: I just wanted to make sure we heard that. And, Shira, I'm going to build off of your comment about the Tribal Epidemiology Centers. I just want to thank you for your comment that is there. And I was wondering if -- I've got two questions. One is, what is the relationship between the Tribal Epidemiology Centers, which I really appreciate the comment about we appreciate our TECs and we would like to see them, you know, utilize more and a greater sense of aggregating information between what comes in the electronic health record in the IHS system and what the Tribal Epidemiology Centers can do. Appreciate that. CDC has funded an MCH

epidemiology positions working with states and cities. I recall that from my City Match days. Thank you, Doctor Bill Sappenfield and others who have invested in that in previous times. So, when we have epidemiologists funded and empowered with access to good data, good things can happen. So I'm wondering, can you talk more about what it would take for the Tribal Epidemiology Centers, particularly with an MCH focus that Doctor Pattara-Lau might be able to lift up as she gets beyond her first trimester of being in her new position, and how to align the work of the MCH epidemiologists in the Tribal Epidemiology Centers with the other MCH epidemiology work happening with the support of states and localities so there can be an alignment of that influence, given that 70 some percent of Indigenous folks wake in urban areas, at least off reservation. So, I was just wondering who can speak to that potential, because that could be very concrete and stronger too, if it were aligned with other investments that are going on to build the infrastructure for MCH

epidemiology.

LORETTA CHRISTIANSEN: So, I'll try to tackle this, but you're definitely pushing all the boundaries today. So yes, I mean, I think the TECs are a very interesting entity, and, quite frankly, there's been a lot of shifting in funding. So, we're going to have to kind of see how some of that shakes out. I think that, yes, could we -- could we look into more funding, could we look towards specifically MCH, of course, those could all be on the table and are all extraordinarily important. I think there are several goals. And, again, I will not speak for the TECs. They're Tribal Epidemiology Centers for sure. But wouldn't it be great if everyone hooked up what they're doing and the data and we're all kind of having the same goals of what we're collecting and what we're aggregating so that we could actually see a true picture of what we're facing? I agree with that completely. I'm hoping that's the future. I know I've had some meetings with CDC, NIH and other agencies on how do we get

some common data, how do we work together, you know, not separately all trying to pull data from places that we wear everybody out, but more like a very concerted effort to get meaningful data. Like what can we use to impact outcomes, not just that we have a lot of data. So, I think that's all extremely important, and certainly something we would be interested in to look at our populations across. I think improving and increasing our relationships with the TECs is vitally important, how can we support them. Again, my Public Health Service teams came to me and said we think that they could deal with more data, they've done a great job, they've used it well, we think they'll do fine with it, no problem, do you think we could widen, you know, what they could ask for in data. And I said yeah, we can definitely do that. That's the way we support them is giving what they need to do what we also would like them to do, which is really look at their tribal communities and really be able to look at cancer data, MCH data, their SDOH-type data and those things that

are very important to us as we plan. Because, even as IHS, how do we plan? We look at what's going on in Indian communities in our Native communities and say what do we need to help with, what can we support, what do we have to provide technical advice over, what's our goals. And that's what we want is that feedback too, so we know where to direct energy as well so that we get what we need. So, I will take that back, certainly, and bring that up. You know, I haven't been -- I've not been at headquarters very long, so I'm still learning some things as well. And I have to go back to my team and say what's the history of this, where did we get stuck, what do we need to move forward. So, I'm happy to do that.

I also have good relationship with the others in looking at data as well, and I'm happy to have a group conversation with them as well so that we can get more coordinated and really make an impact on outcomes.

And then the community health worker

statement -- thank you very much, Doctor Ramas -- yes, it is. Now, this may just be my personal thought, but it is my priority thought too that we have to take more care out into the community. You know, we can't possibly get everybody into our facilities. You know, is there enough access, number one. Do they have to travel too far; definitely. You know, are there roads, you know, can anybody afford the gas anymore. You know, anything like that that would prohibit people from accessing care, we have to mitigate that. So, we're pushing very hard to get everything back towards the communities. We just had a meeting on cancer care prevention and treatment screening in the communities because that's the goal for our program. So yes, we are trying to expand our -- you know, we do use our CHRs, which are called community health representatives, which are the tribal -- the tribes typically are -- that's their staff, but we work very closely with them at our facilities. They do all the investigation for STIs. They do the health checks. We couldn't

have gotten through the pandemic without them. Let me just say that. So, I totally support that out there. And, actually, we're advocating for nontraditional providers to be reimbursed for their care, and that would include community health workers, behavioral aides, peer to peer, dental, you know, the dental assistants that are needed in some areas where there's no dental care. And it would include navigators. It would include a lot of things out in the community to help people access and get the appropriate care. So absolutely that is a model that I'm looking forward to. Even our public health nurses don't get reimbursed for their visits, and they do amazing work. You know, our pharmacists run a lot of our clinics. They do amazing work. I said you've got to look out of that box. We provide care with what we have in our communities. And if it's a community health worker, great. If it's this person, great. We need the care. We need someone out there touching base with the patients in their communities that know them, that speak

the language, if possible, at all, and to check on them. Like they know where every single person lives. I don't know where every single person lives in those communities, but they do. And even during the pandemic, that's how we vaccinated at home. They told us these 3,000 people can't leave their home, they don't have a ride, they're scared, they're sick, they're disabled. Fine, we sent all those vaccines out into the community and vaccinated them at home. That was our CHRs that helped us navigate that. So, I am completely in support of that, and I look forward to that progressing as we move along.

CHAIRMAN EHLINGER: Doctor Pattara-Lau and Doctor Christiansen, when we arranged the schedule we set you up for an hour, but this has been a -- it's been a really good conversation. Would you be willing to stay a little bit longer to take a few more questions?

LORETTA CHRISTIANSEN: I can stay about 10 more minutes, and then I'm afraid I have to jump.

CHAIRMAN EHLINGER: No. That would be excellent, because I think this is a good conversation and I don't want to cut it short. So, the more time you can give us the better. We'll add at least another 10 minutes, so thank you for that.

Doctor Palacios?

JANELLE PALACIOS: Thank you. This is more of a community voice kind of question for you, Doctor Christiansen, and the community voice comes from having worked with people in the Phoenix area. And with the recent closure of the Phoenix area Indian Hospital, the labor and delivery unit, and the community felt that there was not communication from Indian Health Service as to why this labor and delivery unit closed. So earlier you were sharing that there is a sense that the community works very well with Indian Health Service, but I'm just wondering, would tribal communities say that they feel that way, that they feel that they are working well with Indian Health Service and that Indian Health

Service is meeting their needs? Has there been a formal evaluation asking, not just tribal community leaders in, you know, like in a health director kind of position, but additional leaders from different -- additional people from the community?

LORETTA CHRISTIANSEN: Well, you know, I think that's a really great question. And I have to say the number one issue that almost is inherent across the country is communication. You know, you do your best to communicate, and you invariably are missing people for sure. I think that what's really important, and I know that it was -- you know, it's never been -- nothing's ever been perfect for sure, but the pandemic really disrupted a lot of our normal ways that we communicate. You know, we tried to adapt very well. I know that the closure at PIMC -- I know it was put out in many different ways. It obviously didn't reach some people, or they felt they didn't understand why or maybe not enough information.

And I would love more feedback. I would absolutely love more feedback. I will tell you that, you know, the way, due to regulation, that we can survey patients is very limited in the Indian Health Service. We have to go through quite an ordeal to get surveys approved that we can send out to the community. I would love that feedback. It's something we're working on trying to, if you will, modernize that effort because I would like to survey our own staff and say, you know, what do you need from us, what is not happening for you. Because remember, 70 percent of our staff is American Indian and Alaska Native. So, I need that input, too. So, I take your point, and I wish I could just do that right away, but it will take a little bit more concerted effort, which we're willing to do for sure.

The best way I've gotten feedback -- and, again, it's not ever always. When I was at the area service unit level, I had community town halls. Sometimes I'd get three people. Sometimes I'd get 20. But I would ask them questions, how

do you want me to communicate, what's the best way to tell you something, what do you think we're doing well, what do we need to do better. And, you know, you take a lot. They're not happy a lot of the time, but very valuable information is gathered from community input. And I do totally support that all of our service units take the time to do that, not just the leaders from the community, but the people that are getting care, you know, what they felt when they came into the facility, what they needed, what they would have wanted to happen, because we can't improve our system if we don't have that constant feedback. So, we're looking for ways to do that. You know, we're working on a patient experience survey, which will help us some, not all. And then we need to be very open to that feedback because I don't think you can improve things unless you get that feedback. Because I can think I'm doing a great job, and if you come in and say I hated this, you didn't do well at all, then I need to know why you think that. So, I think that is the

customer service side of what we need to work on. That is something that is very important to us, and something I hope to see improve over time.

I will add that our new program in trauma-informed care, which is mandatory training for 100 percent of our staff, our volunteers and our contractors is for them to understand trauma-informed care and address people accordingly. Because I think that it's easy to get in the habit of working and just getting people through the system. What they need to do is make that connection and make sure they're being respectful and sensitive to what people may be going through, maybe why they don't want to come into a facility, and certainly, even our own staff when we deal with our coworkers, are we being sensitive to what might trigger them, what they've been through, what they're carrying around while they're trying to provide care to someone else. So, it is our goal to roll out this trauma-informed care and change the organization. It will not happen right away, but it will happen. And that way we are

approaching things in a way that is so much more respectful and sensitive. And I think we can communicate much better that way. So, we are definitely taking a very hard look at that. Thanks.

JANELLA PALACIOS: Thank you. Thank you for your comments and thank you for being here. I know that it's difficult being in a hot seat, and it's not really hot. I hope it was just a bit warm. And I want you all to know I really appreciate the work that you are doing, that everyone at IHS is doing. It is -- the concern is not necessarily the system of Indian Health Service. It's the parent. Right? It's the way that it was set up. So, my heart goes out to all Indian Health Service employees and Doctor Lau for being here and, you know, giving your compassion and for staying in the long haul. I hope you all do. I have family members and friends who work with Indian Health Service, and I was a patient, and my family members are patients.

This is more philosophical. You do not

have to answer it. But the way that Indian Health Service was set up, was it set up to succeed, or was it set up to fail? And that's just something that I think about from time to time as we move forward, because the -- certainly the funding issues and year to year not knowing if you're going to get your funding is a huge concern because you have no idea what kind of programs you can do, let alone all the issues that we are having with data, with working on community relationships and with really trying to improve Indian health in general when you have so many other factors at odds. Thank you for the work that you all do.

CHAIRMAN EHLINGER: Thank you for your comments, Janelle.

And before you leave, I just have one question to leave you with that maybe you could help us out. We make recommendations to the Secretary of Health and Human Services about how to reduce infant mortality and reduce maternal mortality, and I know you can't tell us which

recommendations we should put forward. But, you know, when I would hide Easter baskets for my kids, I would say, you know, you may want to look in this direction, or you may want to look in that direction. Are there some guidelines or some directions you would like us to start looking that might be helpful, that may help you in terms of help us help you do the job that you're supposed to be doing? So, do you have any clues on the direction we should be looking, the questions we should be asking, the people we should be talking to so that we would come up with the right kind of information to form the best recommendations to the Secretary as possible.

LORETTA CHRISTIANSEN: Okay. Well, that's a great question. I guess I'm going to just kind of frame this in the following way. I've had a lot of these calls this week, by the way. I was on with the CMS Rural Health earlier today. The same type of questions came up. And I guess the first thing I'm just going to say right up front is I think a lot of agencies are using

the term equity, and I'm going to look at equity slightly different. You know, equity implies we all started from the same spot, and we kind of all know that's not true. So, how do we establish a true equity where we are on an equal footing to provide services in the best possible manner at every single site. And a lot of that would do with is -- things that we can do is the diversity of our workforce. We need to be able to reimburse for nontraditional staff. You know, we had probably the most nontraditional vaccinators of anybody in this country during the pandemic. We trained everybody we could train to do it, and we got it done. Same thing with getting out in the communities, how can we support community health, how can we get those workers reimbursed, not because we're going to make a lot of money out of it. It's not that at all. It's to support our systems, and to be able to hire more people. You know, how are we going to get, you know, equal access to telehealth when we have broadband deficits in 40 to 50 percent of our communities.

So can we get telephonic reimbursement, because a phone call is better than nothing for sure that we can call and check on somebody, how are you doing, read me your blood pressure numbers for the last 10 days, etcetera.

So, those are two big things that came up that are very, very important. And I think the third one, which is a much bigger project, is the expansion of our graduate medical education into tribal communities. We need to be able to get providers out there, show them what rural healthcare is like and try to encourage them to become part of our services, but we can't do that unless we have some framework. So we've been working with both the VA through their 403 Mission Act and CMS to give us an alternate pathway to support graduate medical education and place residents in hard-fought areas where we don't have a lot of providers, and also to train residents that are then very amenable to serving our tribal communities in an appropriate and cultural way, not just throwing them there, but making them part

of those communities and part of the solution to those problems.

So, those are very important things when we're looking at healthcare in rural -- and the last -- the last thing I'll just pitch out there is even an emergency EMS training out in the field. You know, we're very far apart. We need some -- we need to uptrain our EMS so when they respond they're able to take care of some of our problems out in the rural areas, certainly communicating back with the hospitals, but not having to always drag that patient all the way into the hospital for them to sit and wait for somebody to see them and then they don't have a ride home. I think we need to take the care back out into the rural area and refine that care for our rural population.

So those are just the tangential ways of me saying what I think would be helpful out in Indian Country.

CHAIRMAN EHLINGER: Thank you very much. Lee, you have your hand up.

LEE WILSON: Yeah. Thank you, Doctor Ehlinger. First, I'd like to thank Doctor Christiansen, Doctor Pattara-Lau and Ms. Carr for taking the time to be here with us and to, as Janelle had said, sit in the hot seat, which hopefully wasn't too hot but was just very intent on getting some answers. I know that for all of you your tenure in these positions has not been that long, and I know that you -- from personal experience working with IHS, that you find yourself in a lot of positions where there are competing expectations, competing demands, and, you know, sometimes balancing the needs of maternal and infant health versus making arguments for funding for construction facilities and water and sanitation. They're not -- they shouldn't be competing with each other, but they are for the scarce resource, which is your time, and so I appreciate that.

I also appreciate the measured, thoughtful, and insightful approach that you've taken to answering the questions for the

committee. As a federal employee, I've sat and cringed a couple times wondering how do you respond to questions when this is the agency that you're representing. And I think you've done a masterful job of that and showing that you and we are all committed to trying to improve the public's health here.

What I'd like to put out there for future discussion, because I don't want you to feel that we are asking for something immediately from you is, as Doctor Ehlinger had said, there will be another meeting that we are planning on doing in September focusing in on the recommendations that are going to be made. I know that IHS thinks about these issues regularly, among the many other issues. And rather than coming up with your own personal recommendations, which some of them you've provided, but are there particular priorities that the agency is working towards when it comes to issues of delivery, or issues of education, or issues related to bundles in facilities that you would like to articulate

for the committee so that the committee can determine whether or not it wants to then say we reinforce that, we will amplify that in our messages to the Secretary and to the Hill and to anyone else who would like to listen. So, we will hopefully be able to continue this conversation between now and September. And if you have any thoughts, ideas, recommendations that come from the agency or from those that you work with, we can collect that, share with the committee for them to then use it in their deliberations in September.

OPEN DISCUSSION

CHAIRMAN EHLINGER: That reminds me that our plan is we're going to have a little workgroup -- and I've talked this over with Tina, Doctor Pattara-Lau that she would be willing to meet with us during the summer to, you know, share whatever information she has with the smaller working groups so we can clarify where we're going so that nobody's surprised that we're working in -- we're rolling in the same direction. So, I hope

that we can do that over the next couple of months as we prepare for September.

Janelle, did you have one more comment or -- Okay. So, thank you, Doctor Pattara-Lau, and Doctor Christiansen and -- what happened to -- Elizabeth. I think she's still on. But, you know, we really appreciate your time.

We're going to have just sort of a general open discussion, and I'm hoping that we get some feedback from and some questions from our other federal partners about what they're doing with American Indians, Alaska Natives in the next half hour or so. So, you're welcome to stay on and listen to that if you'd like. But I really do appreciate your coming here and responding to the questions as -- like Lee said, you were very measured and straightforward and candid as much as you could be, in those conversations and responses. So, thank you very, very much.

All right. So, I want to take a look and see are there any of our federal partners or ex-officio members who may want to have some

comments about, you know, what they heard and what it stimulates in their mind about how they are or should be interacting with the American Indian Alaska Native community from their perspective. So, any thoughts from any of those?

DANIELLE ELY: Hi. This is Danielle.

CHAIRMAN EHLINGER: Yes.

DANIELLE ELY: So, one of the things I wanted to address that I have been hearing as a part of these talks today is, how in many of the reviews of American Indian and Alaskan Native data we are using multiple race data and not just the single race data, as given by OPM. And so, I believe Doctor Pattara-Lau made the comment about the National Vital Statistics System, which is what group I'm a part of essentially, and the desire for multiple race data for AI/AN, and I would just like to bring up that we do have that data available. It is in our data files, and it is actually available on our CDC WONDER website. And even going even further than that, you know, if the group is interested in any statistics

related to the birth files or the linked infant death files that I manage, you know, we can provide some data on multiple race AI/AN if that is requested.

CHAIRMAN EHLINGER: Excellent. Thank you. Any further federal partners?

CHARLAN KROELINGER: Hey, this is Charlan. Just to echo what Danielle brought up, we are also considering the definition of race and ethnicity and looking at multiple races to disentangle how we can increase that number of American Indian and Alaskan Native members to our analyses when it comes to maternal mortality and other topics. So, I think that's a really important point, and a great presentation by an earlier panelist.

CHAIRMAN EHLINGER: Thank you, Charlan. Anybody else from our federal partners?

LEE WILSON: Ed, I have some if you would like from HRSA.

CHAIRMAN EHLINGER: I'd love it.

LEE WILSON: Okay. So, these are

updates that we had provided in support of our Tribal Affairs Working Group. We meet with tribal entities to update them periodically on the activities that we're doing around tribal groups, so I'll just run through them very quickly.

HRSA's Healthy Start Eliminating Ethnic, Racial and Ethnic Disparities Program improved health outcomes before, during and after pregnancy, and reduced racial-ethnic differences in the rates of infant deaths and adverse perinatal outcomes. The program awarded tribes and tribal organizations two grants totaling $2.3 million. These funds include a one-time supplement for $80,000 in funding to address infant health equity for one Healthy Start grantee that is a tribal -- a tribally designated organization, and that is the Great Plains Tribal Chairman's Health Board in Rapid City, South Dakota and Inter Tribal Council of Michigan. I'm in Sault Sainte-Marie, Michigan. That looks like a couple different things. Anyway, it's the Inter-Tribal Council.

As we said, our MIECHV Program administered by HRSA and ACF, which funds the Voluntary Home Visiting Program has a Tribal Home Visiting Program that is run out of ACF and provides grants to AI/AN tribes and consortia of tribes. It administers 23 five-year competitive awards to tribal entities at $12 million per year. In FY 20, the home visiting served 3,315 parents and children, 1,606 families, and conducted 17,129 home visits. And MCHB awarded $10.7 million in ARP funding to 24 new Pediatric Mental Healthcare Access Program Award recipients, which included two tribal entities, the Chickasaw Nation in Ada, Oklahoma, and the Red Lake Band of the Chippewa Indians in Red Lake, Minnesota. The Pediatric Mental Health Care Access Program recipients were awarded up to $445,000 per year for five years to promote behavioral health integration into pediatric primary care.

Healthy Start Technical Assistance Support Center continues to offer educational webinars, including strategies to strengthen

health equity programs, fatherhood programs and quality improvement. Between March through June 2022, the Healthy Start TA Center will offer educational webinars that are available for tribal entities including Fatherhood Talk Tuesday, The Equity Table, Route Learning Academy, which is Restoring Our Own Through Transformation, a two-part series focused on exploring structural and social determinants of health, Understanding Prenatal Alcohol Exposure and Preventing Fetal Alcohol Spectrum Disorder, and the Equity Table Session, which focuses on fatherhood in the age of mass incarceration. Those cover most of the activities that we have reported to the tribal Council.

CHAIRMAN EHLINGER: Thank you, Lee. And maybe you could send that list to me, and I can share it out with the committee, so they know all of those activities going on.

LEE WILSON: I've got it right here.

CHAIRMAN EHLINGER: All right.

MAGDA PECK: Ed, can I ask a question?

I really appreciate getting this update, Lee, and Charlan gave a lovely array as well. From an MCH -- specific to, hopefully, maternal, and infant mortality, but from an MCH investment between HRSA and CDC, or even -- is there any consolidated budget investment to look at it as tribal, or is it sort of within this there's tribal, within that there's tribal? I'm just trying to do some visual mapping about where the investments are going, given that there is not a mandated universal budget, or universal investment we can also argue and support. I'm just trying to get -- it feels like it's scattershot from a big picture perspective, and very strategic from an individual funding perspective. So, how do you, when you go to the Tribal Affairs Council and you -- do you ever line up where the money's going, for whom, for what, with what data base and evaluation and outcomes accountability? I'm just trying to get some sense of money coordination if there's not data coordination.

LEE WILSON: So, that's a very good

question. Would that everything were as orderly as it would be if you were to draw it out on paper. I think some of our activities have evolved over time with a clear measure towards tracking how we're spending our money towards different populations. However, we also have funding streams that are targeted towards specific interventions, and sometimes they overlap with each other. So, we do try to coordinate across the tribal activities. And in our -- I believe we've done some reorganizing at the HRSA IOA level. I believe it's now located in our Office of Intergovernmental and External Affairs, which is where our tribal activities are sort of located. If that's not correct, we'll get you the name. It was in a different office before. But that was the office that was trying to make sure the tribal activities that we're focusing on -- not only tribal but were focusing on the American Indian, Native Alaskan population were being thought about deliberately. So, you know, as we have a health center program, we don't have a set-

aside that says, okay, that's going to this and this is going to that, because it does beg the question of, if that's the case, why is it not in Indian Health Services sometimes versus in these other programs. And I think we try very hard not to be territorial in that sort of way. But there are funds that are provided to IHS to do IHS activities, and then there are funds where we have the Healthy Start Program, and we are expected to serve the nation. And so, in serving the nation, we try to make sure that we are covering rural, we are covering border when border has been called out as a specific initiative, urban, tribal, Hispanic organizations, and jurisdictions. And so, there is -- there are these multiple overlays trying to count.

Our tribal Consultation Program at the HRSA level is relatively new only in the last couple of years. We had been doing this as a part of a larger departmental tribal Consultation Program. So, I think we're still working out some of the activities about what are the structures

that we're putting in place, are we counting dollars to match with the various strategies. And I'm making notes as we're having these conversations about recommendations that we can provide. But that's a little bit of the context here.

And maybe one of the things that we would do that I can pursue is having our tribal Affairs folks be a part of future meetings as we're having these conversations. I know one of our presenters is going to be with us from OPAE, our Office of Policy for the agency. So that's the HRSA response. I don't know, Charlan, if you want to jump in and talk about your approach to this overlapping discussion in priorities.

CHARLAN KROELINGER: Actually, Lee, I think you framed it very well. It's similar for us at CDC. We do have an Office of Tribal Affairs that I can provide a link to for further discussion. They handle our tribal consultation, similar to what Lee described for HRSA. And, similarly, we have those funded line items. And

we tried to be strategic with our different lines to target some activities to support and work with American Indians and Alaskan Natives.

MAGDA PECK: That was very helpful. It kind of was pulling back the curtain of the Wizard of Oz. So, thank you for allowing all of us to hear that your efforts are there. And it's very similar in a mirror way to Doctor Pattara-Lau's new position of trying to coordinate MCH within IHS, how are we trying to coordinate tribal health outcomes for women, children, families, and fathers across federal government or at least within HHS. And there's no analogous person or point of accountability that exists that I can hear at the level of the Secretary. And I was thinking back about the recommendations.

Janelle, you put it out, you know, that if you want to -- and I'm going to cite that just for a second. But in the healthcare chapter or at least in the Broken Promises Report, there was a statement that said just relative to data, you know, accurate data are necessary. And it says,

you know, Congress should provide funding to establish an interagency workgroup to share systems, data methodologies so that we can have an accurate and disaggregated data on populations. And so, the idea that there is an interagency working group, you've got a counselor here, you've got an office there, but there's no -- there's no nexus for the population that we are passionately focusing on, which is women of child -- or people of childbearing age, infants, families, and fathers. And so, I -- there's an opportunity here that we could be a stimulus for that kind of coordination around something specific to start, if it does not exist, and you're telling me it does not exist.

LEE WILSON: I think that -- just to build off of this, you know, to take it a step further, the area where we're really trying to make a difference, at least at the program level for me in our division, is to have these discussions before we're making the awards, as opposed to doing the counting after the awards are

issued so that we're saying, okay, if our intention is to engage with tribal communities for Healthy Start or in Maternal Health Innovations, how do we engage with IHS, how do we engage with the organizations that might be applying for these funds so that we know what -- you know, what are the things that they can and can't do, can they turn around an application in the time that we're allotting, do they have the data to be able to demonstrate need, and are we offering up a model or a program that is something, A, that's going to be appealing to them, and, two, going to make a difference for their population. And that's consulting with IHS, that's consulting with these other groups. And so that's what we're trying. Sometimes we're successful; sometimes we're not so successful. But it is the benefit of having gone around this barn a couple of times now to see, oh, yeah, now we're counting, but maybe as we're competing the next program will take the time to get to that.

MAGDA PECK: That's very helpful.

Thank you, Lee.

CHAIRMAN EHLINGER: Thank you, Lee. Comments from anybody who hasn't spoken so far? I mean any thoughts on what you've heard so far today, and particularly in the last hour and 15, 20 minutes? Any thoughts?

KRISTEN ZYCHERMAN: Is it alright if I just share a little bit about the CMS work related to that?

CHAIRMAN EHLINGER: I would love it. I would love it.

KRISTENA ZYCHERMAN: All right. I'm just dropping in the chat that the CMS Office of Minority Health has put out a report on advancing rural maternal health equity, so I am putting through a link to that.

Additionally, we partnered with the Office of Women's Health on a challenge.gov price competition for postpartum health equity related specifically to black and American Indian and Alaskan Native postpartum people related to hypertension follow up, diabetes follow up,

postpartum depression follow up, various other postpartum activities. That was -- that prize competition is closed, and we are just finalizing the press releases on the winning entries for winning programs that submitted for that. We actually had 62 applications for that. So, a lot of great work is being done. And the winners for that will then be allowed to move on to phase two of the competition of scaling and spreading their already evidence-based programs to help that population in the postpartum period.

So, those are our big things, along with the postpartum care extension, as you're aware, that more and more states are applying to. Additionally, we have our Postpartum Care Affinity Groups and our newly launched Low-Risk Cesarean Delivery Learning Collaborative where that affinity group expression of interest is due July 15. So, states can express interest in being a part of that as well.

And I know from our Postpartum Care Affinity Group, there are states that are focused

on the American Indian and Alaska Native populations within their states as a kind of population of focus for their quality improvement projects related to postpartum care. So, it'll be interesting to see if any states choose that same focus for the Low-Risk Cesarian Delivery Affinity Group projects as well. So, thank you.

CHAIRMAN EHLINGER: Thank you, Kristen. I really appreciate it.

Shira, you have your hand up.

SHIRA RUTMAN: Thank you so much. I know I've been bold on sharing some just questions and resources in the chat, so thank you for your patience with my communications. I just was wanting to clarify in following up with Doctor Peck's questions about kind of coordinated funding, and the note that I included around the funding that did exist that limited competition, cooperative agreements through the IHS for the MCH program, and I was just -- I was just wanting to clarify, and thought maybe Charlan or others could do that, that that funding actually came through

the CDC to the IHS, and it just -- I just wanted to bring it up and ask about that as a question because I think I viewed that as an example of funding that was coordinated. It was focused not only on the data and surveillance that Magda mentioned, but also on some of the interventions that have been described today through these regional efforts that were community based. And so, I understand, and I heard the representatives from the Indian Health Service talking about, you know, various relationships and transitions in terms of work with Tribal Epidemiology Centers. But just in thinking about that as a model in general for funding and activities that were actually based on the MCHB performance measures, we all had advisory councils, and it was a very comprehensive program. I believe it was seven years or five years that it went on. And I think, as you all know, I feel like we all felt like we were just getting started with some of the activities that we were able to put into place when that funding ended. So, I just wanted to

mention that as a potential model for consideration, even if it isn't limited competition, but just to be considered. And I wasn't sure if I was correct that those funds to IHS were actually from the CDC, so that was a clarifying question too.

CHAIRMAN EHLINGER: Thank you, Shira.

All right. We've been busy. We've been busy. We've been very, very busy. We do have a couple of members who joined us. Belinda, would you introduce yourself? You can unmute.

BELINDA PETTIFORD: I'm sorry about that. I am Belinda Pettiford. I'm here in North Carolina at the Department of Health and Human Services, and I'm head of the Women Infant and Community Wellness section. So, I'm so sorry I missed being with you all earlier.

Am I answering the question, Ed, that you sent us? I just was looking at it.

CHAIRMAN EHLINGER: Yeah. What will it take?

BELINDA PETTIFORD: What will it take.

What would it take if we prioritize, and we really listen to our communities' and individuals' lived experience in moving this work forward and actually do what they're asking us to do? I think that is near and dear to my heart throughout my whole 35 years of working in public health. My meeting earlier today was we had been requested by our Legislative Black Caucus of our General Assembly to come and talk about our sickle cell program. So, we have learned over the years that we don't go talk by ourselves. We bring people with that are impacted. So, we had five individuals to come and share their challenges and share their concerns. And, you know, they talked about, you know, how they're treated in hospitals when they're looked at as being drug-seeking individuals and trying to just do basic pain management, and they talked about their quality of life, and discrimination, and the things that they really need. And they keep telling us that, and we continue not to meet those needs. So, what would it take for us to actually, you know, do

what they're asking us to do? So, I think that is what my response would be today, Ed.

CHAIRMAN EHLINGER: Thank you, Belinda.

And, Paul, glad you could join us always.

PAUL WISE: This is Paul Wise. I'm driving in the car. I'm on my way to McAllen, Texas. I apologize for not being able to join on video. I really appreciate the presentations and critical discussion that I've been hearing all morning. It's very important, and I'm glad that it's been put on our agenda.

In terms of answering your question, Ed, my feeling would be to give community groups more money to use at their discretion, to allow them to take more risk, to not be so risk averse -- we're always trying to please the funders' priorities -- and have more power to use more funding for their own purposes. So, thank you.

CHAIRMAN EHLINGER: And thank you, Paul. And I'm not sure if you're going to be with us tomorrow or not because I know you're doing a

lot of stuff, but I know that you're going off of the committee. Please accept my thanks for all of the work that you've done, for the leadership that you've given both for this committee and what you've done over the years. You and I have sort of worked in parallel at least for 45, 50 years, and your voice in maternal and child health has been very powerful, and it continues to be very powerful. So, I hope that we will continue to be partners in this effort for a long, long time. So, thank you for all your work, and God bless.

PAUL WISE: Thank you, Ed. Thanks for your leadership. And it's been a privilege to participate and learn from the other members and the others that have joined us over the years. So, thank you all.

MAGDA PECK: Thanks, Paul.

CHAIRMAN EHLINGER: All right. Now we're to the point where we're going to do some breakout sessions. The first breakout session -- and we are going to look at the recommendations that we put together. So, as I said at the

beginning, these recommendations, there's a lot of them, you know, and they're in -- they're sort of like spaghetti thrown against the wall. Some of them will stick. Some of them don't need to stick. Some of them, you know, need to be highlighted a little bit differently. But they've come from the work that we've done over the last year. They've come from the reports that have been written by a variety of groups. And I've broken them down so that we can look at them from two angles. This first time is going to be looking at them from the lens of our workgroups. We are Data and Research to Action Workgroup or DRAW, from our Health Equity Workgroup and our Quality and Access to Care Workgroup because there are components of each of those -- components of those recommendations in each of those categories. So, what we're going to do -- and I've asked the leads of those committees or those workgroups to facilitate the conversation. And I had some questions in the document, you know, do these recommendations address the most pertinent issues,

are they lacking anything, do we need some other issues addressed, are some of them too general or irrelevant, should some be thrown out, should we combine some of them, should they be reframed as expectations and not just make an assumption like what we did previously, we assumed that, you know, and as a sort of a given, as opposed to having a recommendation, and then what background information should we need, and then what other questions do we need to know before we can finalize those. So those are general questions for both this session when we're looking at it from the lens of the workgroup, and then tomorrow the same questions when you're looking at it from the lens of a specific issue, just like what Magda was talking about, you know, there's a general view and then there's the -- the sort of overall view, and then there's sort of the program view. So that's what we're going to do.

So, I'm going to assume that we will break up fairly equally into these committees, but I'm not sure how best to do that. I can leave it

up to you to choose which one to go to; otherwise, I could assign, but that's going to take too much time. So, I'm just going to -- I'm going to trust that when we give the three workgroups, you're going to choose the one that's most appropriate for your input, and it's going to be equal. But also, I'm hoping that -- you know, we've got several members -- we've got seven or eight members who are going to be leaving SACIMM, and for two of the workgroups, the leaders of those workgroups are going to be leaving at the end of September this committee. So, we're looking, you know, at least for the remainder of this year somebody to lead the charge in those areas. So, I'm hoping that some of you will say, yeah, I can take the lead in Data and Action, Research and Action, or I can take the lead in Health Equity. Steve, I'm assuming -- I'm hoping will continue on with the Quality and Access to Care. But so be thinking about taking on that leadership role in this workgroup, which will continue through the end of this year. After that I will then leave it

up to the next chair to decide whether or not they want to continue these workgroups, because it'll be off my hands at that point in time.

So, Emma, are you going to break us out?

EMMA KELLY: Yes. So, everyone, the link is on the screen as well as in the chat. When you go to that page, it will have day one and it will list all three zoom breakout rooms. Please click the link to the Zoom Room that you wish to attend, and this will be a traditional Zoom meeting. This webinar will remain open. So, once you are done in your individual breakout session, you can come back to this main link. And then we'll be rejoining in about an hour.

CHAIRMAN EHLINGER: All right. So, it's now 3:30 Eastern Daylight Time, and we'll come back at about 4:30. So you've got about an hour's worth of work. So, we'll see you back in an hour.

BREAKOUT SESSIONS

REPORT OUT FROM BREAKOUT SESSIONS

CHAIRMAN EHLINGER: All right. I don't know about the rest of you, but I'm getting tired. But I think I can last another half hour, and then we'll get a good night's sleep.

So why don't we just briefly kind of give me an update on what happened in your breakout groups, because what I'm hoping from all of this is to sort of get a sense, I want each of the leads from those groups to kind of -- they'll give an oral report, but get back to me whatever kind of edits they have so that I can consolidate them; and same thing with the group tomorrow, get whatever edits you have, get them back me and I'll consolidate those into a new set of recommendations, and then we'll go from there. So, it's these two groups, two breakout groups looking at these recommendations from a couple of different angles, getting whatever edits, whatever clarification, whatever else we need. Then I'll try to get it back into another master document, and then we'll start working from that right after

this meeting is done. And I'll tell you about that in just a little bit.

So, let's -- you know, let's start with room number one, Health Equity Workgroup.

BELINDA PETTIFORD: So, we had a wonderful discussion in the Health Equity Workgroup. Lots of good feedback. Let's see. We'll try to go in order. I think one of the key recommendations -- first of all, they thought the recommendations were very comprehensive. People did a very good job all of us working together. I think one of the critical pieces that came out in our group is we really feel like we need to put in writing -- we've got to say how important it is to listen to people with lived experience, and how we can elevate that in every area that we can. We need -- and we even talked about, you know, at the beginning of the recommendations, if possible, to have a link for the Secretary to listen to some of the voices of people with lived experience. So have it like in the opening, whether it's clicking on the link to the Hear Her Campaign or the voices

of some of the recordings from other people, any that we can share. But we think it's important, but we also think it's so important that it needs to be integrated into all of the work we're doing around infant and maternal mortality. So, to us, that was kind of like an overarching area that we really feel very strongly about and making sure that that is integrated.

I think on the recommendation side a couple of additional recommendations were suggested. One was around we need a recommendation on accountability, and some we have some language there that we pulled from the Broken Promises Report of 2018, because we really don't have throughout the document accountability areas. So, we did come up with some language for that.

We also felt like there needed to be some recommendations in there around ensuring that there's a way to be engaged with policymakers, whether these are governors, mayors, Congress, the people that control the resources so that they can have a -- we can do a better job of making sure

they understand the impact of what they're funding on the outcomes. And so, we felt like that that was an important piece.

I think linking back to listening to people, you know, we had a conversation especially under the SIDS SUID area around we really need to get a better historical perspective, you know, listening to people who have the history, the experience as to why the numbers are so high. You know, have they always been high? It seems like they're getting higher versus going in a different direction. Is that a reporting issue? Is that an issue that something has changed? Have they moved away from maybe a traditional practice and moved into -- moved from, you know, another practice that may not be as impacting them as positively in some areas. We did have a couple of kind of other things, and I'll send this to you in a Track Changes, Ed.

Did we just lose Ed, or did I just lose Ed off my screen? Am I the only one missing Ed? No one else can see it either. Okay. Well, we'll

just keep talking because it's being recorded.

So, we did talk about, you know, we wanted to change substance abuse to substance use, because we felt like that was better language to use. And we really spent a good amount of time talking about the importance of valuing traditional Native knowledge systems, and providing services, designing programs, policies, whatever it is, especially in working with Native populations. So, we think that this is an important piece that should definitely be included in here.

And I think those were the main areas. I have some more notes and will send them over. But I don't know if there's anyone on the committee that wants to elevate any specific area. But we did have really good discussions. Anyone want to jump in and add something else while we get Ed back?

JANELLE PALACIOS: No. I'm just going to say thank you to Belinda and to the people who joined the Health Equity Workgroup. I was also

fielding another meeting at the same time, so it was wonderful to have this work move forward and have a lot of perspectives on what's going -- what should be changed. Thank you.

BELINDA PETTIFORD: Yeah. As we started trying to prioritize things, I think what we put at the top of the list is we know funding is needed. It's impacting so many different areas of these recommendations. So, we thought funding was a priority. But we also thought the pipeline as part of the workforce development should be one of those areas that we pull out as a priority as well.

STEVE CALVIN: All right. Well, I guess maybe in Ed's -- he'll still be coming back, but group number two, Quality and Access, we had a good discussion as well. We were -- I think it was really beneficial to have ShaRhonda Thompson's involvement in that. She brings a unique and very important perspective. We discussed -- I think there are 24 recommendations under Quality and Access. And just a couple of high points, and

I'll send Ed the rest too. But there was a real focus as well on personal kinds of relationships, because when patients, when moms are just sort of handed a clipboard with, you know, fill this out, or fill this tablet out, it's really important to be able to get direct one-on-one assistance in navigating the system in a culturally-appropriate manner. So, we're -- I think that that's going to be a priority.

There was mention as well of the mental health issue, not just for mothers also for infant and early childhood interventions. I mean especially with what happened in Uvalde, there -- you know, there are some kinds of identifications of really troubled situations. ShaRhonda also brought up the point that partners, husband, fathers, partners of any type really need to be involved in the assessment of those kinds of things.

We have a -- number 12 is a recommendation that was this comprehensive thing that I think is a new HHS program that was some

kind of a residential comprehensive situation which we're just going to get more information about. There was also a mention of telemedicine, and how we all believe in the wonders of it, but there are many communities that either don't have broadband access or really reliable wireless access, or they don't have, you know, the tablet, the phone, the, you know, laptop that would be able to allow them to use that.

And then second to last, one of the members of our group pointed out that there was a mention in one of the recommendations of the word interventions, so interventions to, you know, intervene in a cultural situation. We will -- we'll strike that. Interventions will be changed to some other appropriate word.

And then we did have a presentation at the end by Kendra Wyatt regarding some of the issues related to health information technology, and the fact that interoperability is not working well at all. And there's a whole variety of ways that that needs to improve, interoperability, and

that patients can own their records and kind of take them with them to get the best care that they need, but for sure to change the way the system works. The system is working right now it seems like more for the overall industrial medical system than it is for patients. And so we'll put together a recommendation in that regard.

So, take it away, Magda.

MAGDA PECK: I did get a note from Ed who, like myself, was booted off, and so technology will always get in the way, and we just keep on moving forward, which is what happened in our breakout group when I was booted off in the middle of it.

So, allow me to thank the individuals, the close to dozen folks who joined us. And the way we proceeded was to first harvest what we had heard in the prior presentations on day one that we wanted to make sure was brought into our discussions about the data and researched action recommendation. So, we will -- we just wanted to make sure we didn't go right to the

recommendations without taking into consideration what we have heard, learned, been surprised at, had questions about that can inform the discussion, and I will forward those on to Ed as well with Emma's help.

The second broad brush that we addressed had to do with the recognition that language matters. Intervention is one word that we may want to be thoughtful about, and the nuance of language. And we just want to assure that we are being intentional with the language that we use in what we write in recommendations. Towards that end, a good example of that is in the second data recommendation around First Nations' involvement and participation should be part of, and the language suggested is where is the leadership should lead what is happening. So be thoughtful about what roles we are relegating folk to that might perpetuate some of the structural hierarchy and history of oppression. So, language matters.

We also heard that there's questions

about what language should we use, and folks are hesitant to not want to in any way offend, and the humility, cultural humility that we bring. So, a suggestion came could there be a clarification of terms, an education of terms in the preamble, if you will, a glossary that allows us to educate while we are informing the Secretary as our primary audience. Other audiences will read this, and so the more that we can link to our glossaries and information about what language we can use around First Nations, First Peoples, sovereignty, compact, contract, things that we're learning we want to pass on the learning. So, that's some broad-brush work to do.

We did a three-part analysis to begin with; what do we want to assure we would elevate up of the 15 that we were considering; what may be some gaps that is not yet addressed at all; and the third header is what would we want to clarify and sharpen. And I will not take the time to go in the detail of those now but know that that's the work that we brought to our section.

If there was one thought that I would like to end with which echoes our other two breakout groups and our working groups, it has to do with the second, this notion about individual community collective first-person voice, the power of the qualitative data, the storytelling and listening to people was also echoed in the data group as well. We did put out a recommendation when we first started in our SACIMM cohort about the data should be considered qualitative and quantitative in its value, and that the first-person voices of people and their stories are essential to hear and listen and integrate and follow. So, the recommendation around how do we bring those voices forward appears in recommendation number two as well as in other recommendations that we have that we will look at.

And I guess if there's a final, it's there's so much muddled, disconnected, fragmented data out there that don't talk to each other. And the more that we can harmonize, standardize, make them interoperable, let them talk to each other to

tell the full story, we can see that that would strengthen our capacity to form program policies and practices going forward.

More will be written up. More will be submitted to Ed. And I'm wondering is Ed back on board at this time.

CHAIRMAN EHLINGER: I am back. I heard that, and I heard the end of Steve. Sorry. I somehow got booted off, and it took me awhile to navigate back.

MAGDA PECK: Not a problem, and I just want to say is that -- I want to lead back the thanks to Emma for keeping notes, and thanks to Marie and Joy and others for kicking in when I got booted off. And I just want to pause for a moment to see if there's anything that any from that breakout would like to add that didn't get the emphasis in my presentation.

So, I'm just going to take a pause, Ed, and see if there's anything else we want to hear.

SHARHONDA THOMPSON: I wasn't in your breakout group, but I did want to say something

about the importance of how things are said and how that can make a person feel or respond. I know I'm focusing on infant mortality, but I've always in my own brain switched it. Instead of focusing on infant mortality, I'm focusing on infant vitality, what can I do to make their lives more vital and increase that.

MAGDA PECK: I want to thank you for raising your voice, and I want to hear more of it. And you're always part of the data group, even if you didn't come to that breakout. So more to do together. Thank you.

CHAIRMAN EHLINGER: All right. Well, thank you all for your work. And I cut out just as Belinda was talking about using other mechanisms of getting information out. And it reminds me, you know, there's something called Photo Voice where, you know, people use video and -- you know, we've traditionally over the time that we've been in SACIMM we've said, you know, let's focus on qualitative and quantitative data. Let's focus on different ways of looking at it. I

think we should really think about it. It tweaks in my mind how else can we transmit this information to the Secretary, does it have to be in a letter, does it have to be in a written report. I don't know, but it just struck me let's -- let's be a little creative and see what we can do. I don't know what kind of resources we have to do some of those things, but at least it'll tweak my brain to think a little bit about that.

So, I do wish that, you know, everybody can you know, glean all your thoughts, put them down in writing and get them to me. You know, we can do that at the end of the meeting. And the next breakout group tomorrow we'll do the same thing.

WRAP-UP, OVERNIGHT CONSIDERATIONS

But so let me tell you how I plan on moving forward with all of this. At the end of the meeting, I will be forming four task groups to help us finalize our recommendations, and they're going to focus on four things that I think need a little bit more work to be really totally

clarified; one is the Indian Health Service; one is data because there are data involved in everything that we do; a collection of violence, incarceration and substance abuse, that that kind of category, and then the care delivery and workforce, so four different sort of little task groups that I think will probably I'm hoping will meet once or twice to try to clarify and hone all of these recommendations. And so, I would like to have one committee member from our recently appointed members and one from our departing group lead these workgroups, and then other members of these groups could consist of SACIMM members, ex-officio members and members of our existing three work groups. And so, from my one-on-one interviews with each of you, I have some idea and from what I've heard today about who should lead and be on those task groups, but I would like, actually, you to chime in what your preference would be. So, think about which one of these things you would like to be on, the Indian Health Service group, the data group, violence,

incarceration and substance abuse group or the care and delivery workgroup. And SIDS and SUID, I think, will be part of the discussion of both the data group and the care delivery group, because that's one of the issues that we haven't identified. And so think about that, which one you'd like to be on, and then send me an e-mail before tomorrow so that I can sort of see who we could put on those groups, and I think that will help us with these little workgroups finalize those documents so we can get them ready, and I will put together then a little timeline, because I would like to get this work done by the middle of August, actually, because then I would like to get our recommendations out to others who can critique them, sort of give outside expert review so again we can clarify before we can finalize them in September and then have them actually talked about when we have our meeting in September. So tonight, think about where you'd like to spend a couple of -- one meeting or two meetings on Indian Health Service or data,

violence, incarceration, substance abuse, that kind of category, sort of a catchall category, and then the care delivery and workforce, and then send me an e-mail.

And, you know, then it sort of gets to the point of that I raised the question of, you know, what will it take to get these recommendations finalized. As I said in my introduction, it'll take the involvement and commitment and prioritization of every member of this committee to make that happen. So, I'm hoping that we can do that, with that, any comments that folks have before we sign off for today and meet you back here at noon Eastern Daylight Time? We get a little extra hour in the morning. Any comments before we leave?

JANELLE PALACIOS: Can I ask Anne or anyone from HRSA just how -- what is the turnaround time in terms of the typed-up notes for today and tomorrow?

EMMA KELLY: So, we are currently typing up all of our notes that we took from the

meeting and briefly reviewing them, and I will send them out as soon as our team is done. So hopefully by about 5:30 you should have the notes from the meetings.

MAGDA PECK: Thank you.

EMMA KELLY: And then it usually takes a little bit longer to process the recording. But once we get recordings or transcripts, we can also forward that to you, if you find that useful.

UNIDENTIFIED SPEAKER: Will you give us a different link for tomorrow? We're at the same link as today.

EMMA KELLY: Yes. So tomorrow will be a new link. If you are a panelist, so anyone who's speaking right now, you will get a new link in the morning. I can also -- we'll resend that right before the workgroups break so the link will be again right at the top of your e-mail. And if you are a public member, you will also receive an e-mail from me tomorrow with the link for tomorrow as well.

MAGDA PECK: If you're registered. I

want to thank the -- and just to echo what Charlan said, this has been a very inspiring and provocative day. So, just take a breath with gratitude for all the work that brought us to this moment and to seize this moment as a time to make pivotal change. So, thank you, Ed. Thank you, Janelle. Thank you to all of the speakers. And thanks to all of the SACIMM members.

I just want to add one last thing, Ed, and that is I hope no one holds back. Just because you're a new SACIMM member, or you feel like you might be late to the game, you are our secret weapon, and you have magical powers. Because if it doesn't make sense to you, it doesn't make sense. So, we are all on equal footing going forward, and we hope to -- all of us do much better work together. So, thanks to all that jumped right in and made things happen.

ADJOURNMENT

CHAIRMAN EHLINGER: And those of you who know me, I like history. And today this is a good piece of Wisconsin history, where I came

from. One of the senators in Wisconsin was Robert "Fighting Bob" LaFollette, very progressive. He ran for president and was the governor. He really created Wisconsin to be a very progressive state, and he pushed for women's rights, voting rights, for minimum wage, for worker's compensation, for a whole variety of things. But he said this quote that I love, there was never a better time to work for social justice than right now. And I think that was true back in the Twenties when he made that statement. It's true right now. And I thank you all for being partners in that work for social justice. So, for Robert "Fighting Bob" LaFollette and his birthday, happy birthday, Bob, and we'll continue fighting for social justice with this group, and with every other group that we work with. So, see you tomorrow.

MAGDA PECK: Thanks so much.