1 **The Secretary's Advisory Committee on**
2 **Infant Mortality**
3 **US Department of Health and Human Resources**
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8 Virtual Meeting
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12 September 22, 2021
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1 P R O C E E D I N G S
2
3 **SACIM ORGANIZATIONAL ISSUES**
4 EDWARD EHLINGER: Very well. I've waited
5 for my one minute, so let us get started on this
6 second day of the SACIM meeting, the September
7 virtual meeting on this day of the Equinox, the
8 eternal Equinox when we have the balance between
9 light and dark.
10 Also, the second day of Sukkot, where we
11 will -- we should be inhabiting the experience of
12 being vulnerable, particularly in partnership with
13 all of the mothers and babies and families that
14 are vulnerable in our country.
15 We will start with some business
16 activities. We did not approve the minutes at our
17 meeting yesterday, so would somebody move approval
18 of the minutes from our June meeting.
19 MAGDA PECK: So moved. This is Magda.
20 EDWARD EHLINGER: Is there a second?
21 UNIDENTIFIED SPEAKER: Second.
22 EDWARD EHLINGER: All right, we have a
23 movement and second. And we don't have bylaws, so
24 I don't know if we have a quorum. I know there are

1 a few members missing, but any discussion on the
2 minutes?
3 All right, hearing that, all in favor
4 just wave at me if you approve.
5 Any disapprovals, now wave. All right,
6 then approved, very good.
7 So now let us move into our agenda, and
8 the first item is some of the organizational
9 issues. So, I know that Lee had brought that up
10 at our last meeting that he needed a little time,
11 so he and Vanessa will kind of update us on some
12 of the organizational activities.
13 So, Lee and Vanessa, it's all yours.
14 VANESSA LEE: Thank you, Ed, and good
15 morning to those on the West Coast. Good
16 afternoon to everyone, welcome back. I hope you
17 all did get some time last night to recharge. We
18 had a great first day, I'm looking forward to day
19 two of our time together.
20 As Ed said, Lee and I just wanted to give
21 you a few administrative or operational updates
22 like we've been doing over the past few meetings.

1 Three things that I have on my list is
2 the charter, bylaws, and then bringing on new
3 members. So just to start with an update on the
4 charters, you guys know these -- your committee
5 charter lasts for two years and then has to be
6 renewed. I want to assure everyone we're on track
7 to get the charter renewed by its expiration date,
8 which is September 30th.
9 So as soon as we get the final sign off,
10 we will be publishing a federal register notice so
11 that the public is also made aware of the new
12 charter, and of course, we will send a copy to all
13 of you committee members just to share that and
14 review it with all of you. But again, we're on
15 track to get it renewed by September 30th, which
16 is when the current charter expires.
17 Lee, anything to add on the charter
18 renewal?
19 LEE WILSON: One item related to that, as
20 we have discussed in the past at length, there has
21 been the expansion of the committee's role to be
22 addressing maternal health. And so, as part of

1 the charter and the bylaws, we have worked to
2 incorporate those changes to the mission. And if
3 everything is signed off as expected, that will be
4 reflected both in the content of the charter and
5 the bylaws as well as the title, which will mean a
6 slight change to the title of the committee to
7 include maternal.
8 VANESSA LEE: Great, thank you. Next
9 update on bylaws, we wanted to wait to submit the
10 bylaws for approval so that they were consistent
11 with any changes to the charter. So, they have
12 moved forward. So, we are in process of getting
13 the bylaws approved. And again, the language in
14 that document should reflect any changes we had
15 made to the charter. So, we will keep you updated
16 on that and share them as soon as they're
17 approved.
18 And then the third item I just had was an
19 update on bringing on new members. As you guys
20 know, the charter allows twenty-one members to the
21 Advisory Committee on Infant Mortality, so Lee has
22 been working over the last several months, almost

1 a year, to get those remaining positions filled on
2 the committee, and we are still waiting for the
3 background vetting on our recommended nominees to
4 be approved and fully vetted. So, we hope to hear
5 something before the end of the year.
6 Lee, anything on this current package of
7 nominees that we're waiting for full approval on?
8 LEE WILSON: Yeah, just I would imagine
9 for committee members and for nominees, those of
10 you who have gone through the process as committee
11 members understand how long and tedious a process
12 this is. We suffer internally with the same sets
13 of difficulties with -- you know, we put out a
14 call for nominations, it seems like two years ago
15 and probably is two years ago, and to get through
16 this process, it's laborious both on your side and
17 on our side.
18 The final stage of this, for many of you
19 who know, once we've finally gotten the approval
20 through the various chains is to go through the
21 ethics provisions as well, which are not generally
22 saying is a person a good ethical person or not,

1 rather to say are there any conflicts of interest
2 or financial issues that need to be either
3 addressed or recused.
4 So, it is sort of a silent process
5 because there are personal details that are being
6 uncovered or reviewed through this, which is why
7 it does seem a little shrouded and less than
8 transparent. We are following all of the rules to
9 the letter and -- which also includes us remaining
10 rather silent on who has been nominated and not.
11 For purposes of this particular round of
12 nominees, for a few that you may have nominated up
13 to this point, if they have not been contacted by
14 us for that first round of nominees throughout the
15 process, they are not currently on the list. All
16 of the people who have been -- are being
17 considered for the round one set of nominees have
18 been contacted, have been engaged, have received,
19 or had some back and forth with the ethics
20 process.
21 I did get a question from someone about a
22 week ago who had been on that first list of

1 nominees, and they had not heard yet, and I did
2 let them know that if they hadn't received that
3 input then they weren't being considered for that
4 round.
5 That does not mean that for future rounds
6 we won't look back at the packages that have been
7 submitted to us, so please be assured that that
8 was just the first round of now two that are in
9 the hopper, and we are saving all of those names
10 for consideration And we do remain open to other
11 names for nominations if, along the way you feel
12 they're somebody who would be particularly good,
13 we do keep a running file of those nominees.
14 That's all.
15 EDWARD EHLINGER: We had mentioned, you
16 know, there are some categories of people. We
17 want some diversity, geographic and professional
18 and age and, you know, racial and all those kinds
19 of things. Is there any way for you to sort of
20 say in a word, here are some categories that we
21 would like some nominees for, you know, just to be
22 kind of proactive on that?

1 LEE WILSON: Sure. We have sliced and
2 diced this in every possible way. We have lots of
3 Excel spreadsheets looking at a region of the
4 country and professional expertise, and gender,
5 and race, and all sorts of categories. So, we are
6 trying to -- and those are the requirements within
7 the Federal Advisory Committee Act that we make
8 sure that it is -- our representation is diverse
9 and comprehensive.
10 Right now, we have been looking -- just
11 to give you an indication of what we're looking
12 at, we have been looking at some of the expertise
13 that is on the staff, that is on the committee,
14 that is rolling off the committee. So, if you
15 look at the members who are leaving, the areas of
16 expertise that they bring to the table now, we
17 want to ensure that there are others who can
18 continue on some of those discussions.
19 I think from the pool of candidates and
20 nominees that we have received, we can cover all
21 of those bases, but we will reach out to you, and
22 I believe, Ed, that Vanessa has reached out to you

1 on a couple fronts just to make sure that we're
2 covered with OB/GYN's, we're covered with
3 pediatricians, we're covered with nurse-midwives,
4 we're covered with people from the various regions
5 of the country, and that will be a running
6 dialogue with you all.
7 EDWARD EHLINGER: All right.
8 VANESSA LEE: And just to add, I will say
9 it was difficult to find -- you guys had mentioned
10 early career professionals, and I think we have
11 different -- you know, you can just tell us what
12 you -- how you defined early career. But I will
13 say when we looked for people who were, you know,
14 let's say within their first five to seven years
15 of their career, I know you guys wanted that
16 representation on the committee. I will remember
17 in going through all of the packages you received,
18 that was one of the categories that was a little
19 more difficult to find submissions.
20 And the other was, we're always looking
21 for more consumers or, you know, people from the
22 community. There were several people -- more than

1 several I would say -- that have lived experience,
2 but again, just looking for more of that consumer
3 representative, always happy to take more of those
4 as well in the mix, plenty of professionals and
5 medical professionals, as you would imagine, came
6 forward.
7 EDWARD EHLINGER: Magda, you had a
8 question?
9 MAGDA PECK: Thank you for helping us
10 assure the continuity and strength of SACIM,
11 whatever the acronym will become.
12 Two quick questions. One is in this
13 sense of rounds, how many do you anticipate
14 onboarding if everyone said yes, and by December?
15 And in a second round, is the hope that by the
16 time we complete, many of us, our tenure by June
17 of this coming year, June, July, that we will be
18 at a full compliment of twenty-one? I'm just
19 looking at that sense of what's the end goal if
20 this is a year of transition? So that's the first
21 question.

1 The second question is a technical one.
2 All of us need to be vetted still at regular
3 intervals. It's not a -- it's part of the price
4 of admission, and to be honored to be here. Can
5 you anticipate that we, who currently serve, will
6 need to go through another round of ethical review
7 prior to the end of our terms that may expire?
8 And if there is a third, how many people
9 stay on and how many of us -- of the few of us
10 that are on this committee will be leaving? If
11 you could just give those three points, I think it
12 would be helpful for us to have context for the
13 transitions of the coming year. Thank you.
14 LEE WILSON: Vanessa, do you want to go
15 first?
16 VANESSA LEE: Sure. If all nominees
17 currently being vetted do get approved, it would
18 be nine new members coming on board.
19 Of the current ten of you that are on the
20 committee now, if I'm remembering your term dates
21 correctly, there are seven of you that will roll
22 off next either June, July and one of you, I

1 think, that is September, so we're looking at
2 about seven of you rolling off in the summer to
3 fall of 2022.
4 So that is the new package that Lee
5 mentioned we're preparing and starting to think
6 through, trying to backfill those seven slots, as
7 well as fill any remaining ones, since we didn't
8 get a full set of eleven approved for this year.
9 LEE WILSON: So, as we're moving forward,
10 the goal is to try to get to that twenty-one. We
11 are not allowed in the process currently to submit
12 an extra one just in case someone falls off. That
13 was something that we tried this year, but we
14 failed at, knowing that the odds are that one or
15 two are going to fall off through the year, a
16 year-and-a-half-long process that it takes, that
17 somebody will either lose interest to have a
18 career change or for whatever reasons do not make
19 it through the vetting process.
20 So, our goal is, as we're moving forward
21 to achieve the full compliment of members by the
22 time, we complete package two, but we can't

1 guarantee that that's going to happen. And the
2 goal is to have both a staggering of members
3 because as Vanessa had said, there's a large
4 portion of -- actually the majority will be coming
5 off, existing members will be coming off in the
6 summer next year, so to try to stagger this so
7 that it's a less dramatic change in the committee
8 over time.
9 On the ethics side, Vanessa, I don't have
10 any information on whether or not a re-review is
11 necessary between now and the end of the cycle.
12 VANESSA LEE: Of their terms. I can
13 follow up on that, Magda. You're right, it is an
14 annual review now, so I'd have to ask the ethics
15 of any of you have a review coming up before the
16 end of your term next summer.
17 MAGDA PECK: Thanks for that. It just
18 helps us to plan ahead so that we don't get caught
19 behind and then we're being chased. So, if we've
20 got one more to go, please let us know.
21 VANESSA LEE: Okay. And then Belinda had
22 a question in the chat, and just so everyone is

1 aware if you can see the chat, did we consider
2 individuals with lived experience? Yes,
3 definitely, and we will continue to do so.
4 And then do we -- if you do have
5 recommendations, yes, please just send them to me.
6 I can put my email in the chat if you guys don't
7 already have it.
8 EDWARD EHLINGER: All right, thank you
9 very much, Vanessa and Lee. Anything else from
10 your standpoint, administratively?
11 LEE WILSON: There is one item that I just
12 wanted to bring up with you. So, the discussion
13 yesterday about race concordant care, I thought
14 was a really excellent discussion and something
15 that I welcome hearing the input from both the
16 people that are brought into the providing
17 opinions and views as well as weighing in from the
18 various committee members and maybe where there is
19 consensus on particular topics or on these issues.
20 I would ask as you're having some of
21 those discussions, for purposes of us, and this
22 goes back to one of the questions that was raised,

1 and I'll use a word that wasn't used yesterday,
2 around the traction that recommendations are
3 making or not making as we work through the
4 process of reviewing recommendations that are
5 made, we're looking for every opportunity to gain
6 traction with the recommendations that you have.
7 And I do respect and appreciate the
8 comments that Paul Wise had made around not just
9 letting the bureaucratic process drive your
10 recommendations and whether or not they're
11 considered or not. So, kudos to Paul for bringing
12 that up and bringing back the point of traction.
13 If there are particular topical areas
14 where there is consensus from the committee or
15 strong feelings with a small group on these very
16 sensitive issues, it's helpful for us to hear what
17 those are, and especially if there is consensus to
18 know that, and to consider what is good from
19 different perspectives for purposes of the
20 government to hear. On race concordant care, I
21 think that's a very looming issue for all of us as
22 to how we craft national policy around some of

1 those topics as it relates to case law, as it
2 reports to the way we fund grant programs and as
3 it relates to the types of incentives we provide
4 or don't provide.
5 So, anything that you can direct us or
6 give us your expert advice, it will be noted,
7 recorded, and potentially used as traction for the
8 policy recommendations that we're making, so thank
9 you.
10 EDWARD EHLINGER: Thank you for that, we
11 appreciate that.
12
13 **OPENING INVOCATION**
14 EDWARD EHLINGER: Then let's move into the
15 main session of this first part of our day, which
16 is indigenous health. As you know, when we were
17 together in June, we made some recommendations --
18 we included some recommendations in our overall
19 package of recommendations to the Secretary around
20 the Indian Health Service and indigenous health.
21 But in our discussion, we recognized that
22 it was a much more complicated and complex issue
23 than -- and we had not taken the time to really

1 look at all of the indigenous health issues or
2 going in-depth on any of them. So, we decided
3 that over this next year we would really do a
4 deeper dive into the issues related to indigenous
5 health, particularly among moms and babies.
6 And so, we're going to be focusing on
7 that in the first part of our session today, and
8 I'm hoping that when we get together, our first
9 in-person meeting, which I'm hoping will be in
10 March, that we might even be able to do it on
11 tribal land to really get some firsthand
12 experience of what's going on in Indian country.
13 But today we are going to really do a
14 deep dive for a couple of hours led by Janelle
15 Palacios, who has been taking a lead in this,
16 along with some other experts, other resources in
17 this.
18 But before we get started, when I was
19 State Health Commissioner, whenever I met with
20 tribal leaders, we always started with an
21 invocation. And I found that it really set the
22 tone, it set the stage for the meetings that we

1 had, and they were much more productive, and I
2 really appreciated that at the beginning of our
3 meetings.
4 So today we are going to start our
5 session with an invocation, and I have invited
6 Wakinyan Sky LaPointe, Sicangu Lakota from
7 Minnesota, which is Lakota for the land of cloudy
8 waters.
9 Wakinyan is the indigenous human rights
10 advocate and a co-convener of the Mni Ki Wakan or
11 indigenous water decking. He centers Lakota
12 knowledge, language, and ways of life in his work
13 advancing human rights, particularly his works in
14 partnership with indigenous peoples and with
15 youth. And he's been particularly active in
16 indigenous water rights and water justice and
17 believes in the sacredness of water and our
18 connections with water are also sacred.
19 Now you will see shortly that just by age
20 he is not an elder, but he has been taught by his
21 father, Laymon LaPointe, who has blessed him and
22 given him permission to do these kinds of openings

1 and to be aware that Jackie Dionne, who was my
2 Indian health director at the Minnesota Department
3 of Health, who is from the Turtle Mountain Band of
4 Chippewa, offered tobacco to Wakinyan on behalf of
5 SACIM as part of the invitation for him to come
6 and do an opening invocation.
7 So, what that, Wakinyan, please welcome
8 to SACIM and we appreciate your words.
9 WAKINYAN LAPOINTE: Thank you. Thank you.
10 I'm honored to be here today to speak to all of
11 you as part of SACIM and to touch on this
12 important topic of the health of indigenous
13 mothers, infants, and their communities.
14 At this time what I always begin with is
15 just some words in our language, especially the
16 Lakota language. In our way, we often say
17 (foreign language word), which means our children
18 are sacred or the babies are sacred.
19 In our stories, when a spirit first
20 touches down on earth that is a ceremony in and of
21 itself. When a spirit begins to breathe in this

1 world, that's also (foreign language word), the
2 giving of life, the breath of life.
3 And so, in our way, we always say
4 (foreign language word) which means our words are
5 sacred. They have the power to give life and they
6 have the power to take life.
7 And so, I mention these things because,
8 you know, it relates to one indigenous world view
9 of the Lakota people and how we perceive our
10 children when they first come into this world, and
11 it's by, you know, ceremony.
12 And so, I want to say that importance of
13 that and also the (foreign language word) the
14 woman, the (foreign language word) that are
15 sacred. And it also relates to one of our words
16 of (foreign language word), one of the first
17 creators in which gave all life to creation.
18 And so, we don't take this word lightly
19 in our Lakota way. We often say we do not
20 separate the creator from creation. Our
21 spirituality is our reality.

1 And so, I want to offer a prayer here in
2 the Lakota language. What I will do is, I'll
3 offer (foreign language word). And in our
4 original stories, the spirit of (foreign language
5 word), tobacco, traditional tobacco spoke to us
6 and told us how to pray with it, how to offer our
7 prayers. And it was one of our first ceremonies
8 as the (foreign language word), the seven council
9 fires.
10 And so, as I do this, I want to sing a
11 song in our way and it says that this offering is
12 sacred and this is what we say as we pray, and
13 what we say will be heard by (foreign language
14 word), grandfather, the creator, and our
15 grandmothers.
16 And so, I always offer this as I begin
17 these important conversations together, and we
18 always do it as a community, so I want to say that
19 piece. And I'm lighting sage here, (foreign
20 language word), and we offer this to cleanse
21 (foreign language word) which is to wipe ourselves

1 down, (foreign language word), and then (foreign
2 language word) to make our spirits whole.
3 And often these are ceremonies, too, that
4 are as old as time and go back since time
5 immemorial.
6 So, with that, I have a (foreign language
7 word) with me and I'm going to sing this song.
8 And again, I ask that everyone pray together,
9 offer their good hearts, their good energy from
10 their minds together as one. We say (foreign
11 language words), which is one mind and one heart.
12 And with that, I'm going to go into this song and
13 I'm going to offer a prayer in the Lakota
14 language.
15 (Whereupon, a song and prayer were held
16 in a foreign language.)
17 And so I offered this prayer in the
18 Lakota language, praying for the mothers, for the
19 fathers, for the babies and for the children in
20 this way with (foreign language word), and I ask
21 for this (foreign language word), the spiritual
22 wisdom, this balance in the universe, the (foreign

1 language word), this wisdom within ourselves, this
2 collective wisdom that we hope for in everything
3 that we do within this work and on this red road I
4 prayed for these children, these babies that you
5 seek to help, that they walk on this red road in a
6 good way remembering who they are in their own
7 ways of life.
8 And so, I think that with that I want to
9 conclude my part here and ask that you continue
10 this prayer and this work that you do because it's
11 the stuff that gives meaning to it, why we do this
12 work. And so, with that, I'll conclude my part.
13 (Foreign language word), for having me on here and
14 it's been an honor.
15 EDWARD EHLINGER: Wakinyan, blessings to
16 you. Thank you for your contribution. It adds a
17 lot to our discussion. I appreciate you being
18 with us, and I hope you can stay with us and
19 listen to the conversation.
20

1 HEALTH OF INDIGENOUS MOTHERS AND INFANTS AND THEIR
2 COMMUNITIES: CONTEXT, CURRENT CONDITIONS,
3 CHALLENGES

4 EDWARD EHLINGER: And I now turn it over
5 to Janelle to lead us in this really important
6 session, as most of ours are, but this one in
7 particular, given this time when we're thinking
8 about vulnerable individuals, vulnerable families,
9 and the moms and babies that walk the red path.
10 So, Janelle.
11 JANELLE PALACIOS: Thank you. This day is
12 particularly special in that we were able to have
13 Wakinyan to give an invocation to bless this work
14 that we're doing. And I want you to know that
15 this would not have been able to happen except for
16 a law that was passed in 1970 that allowed Indian
17 religious freedom, a year before I was born, so
18 thank you.
19 Today is Harvest Moon, as Ed had brought
20 up, and the first day of Autumn Equinox. We have
21 days of equal length in the length of day and
22 night are equal. So, it's very timely. We're at
23 a point of position as a committee, as a nation,
24 as systemic racism, with Covid-19, and as members

1 of a global community as we face climate change,
2 which will have great impacts on the most
3 marginalized.
4 David de la Cruz yesterday gave advice,
5 and his advice was to be persistent and not give
6 up, to not be satisfied with the status quo, and
7 to keep pushing to be seen and heard, and that's
8 what we're going to do today. We will start this
9 panel with a visual storytelling of native
10 history.
11 Following this, we will hear from Dr.
12 Susan Stemmler, a nurse-midwife, who has extensive
13 experience with women's health, substance use, and
14 native health. She'll share her observations and
15 perspectives as a nurse-midwife clinician and a
16 researcher reviewing IHS facilities.
17 `Following Dr. Stemmler, we will hear
18 from Dr. Linda Bane Frizzell, who will share with
19 us her experience, her expertise on the Indian
20 Health Service Systems.
21 So, I believe now I need to -- let's see
22 -- I think that we are all the way at the very end

1 of my presentation. Chris, is there a way to
2 fast-track it to the very beginning?
3 UNIDENTIFIED SPEAKER: I don't believe
4 we've received your presentation yet, I thought
5 you were sharing.
6 JANELLE PALACIOS: Sorry, I will be happy
7 to share. And I'm looking at my screen, so I am
8 about to share my presentation. Thank you. Okay.
9 UNIDENTIFIED SPEAKER: You should just
10 need to click the share screen button down in the
11 middle.
12 JANELLE PALACIOS: It's coming.
13 UNIDENTIFIED SPEAKER: Okay.
14 JANELLE PALACIOS: Thank you. Okay. All
15 right, are you able to see the presentation now?
16 VANESSA LEE: Yes, we are.
17 JANELLE PALACIOS: Okay, perfect. So, I
18 will begin because I know I spent a few minutes
19 trying to upload everything. So much technology.
20 And I want to share with you that this
21 presentation is gigantic, and I was not able to
22 share it very easily.

1 This is a visual storytelling of
2 indigenous history, which is going to help
3 background the context for our discussion later,
4 and for future conferences that we have.
5 So (foreign language word), good day
6 everyone. Thank you for joining me today as I
7 share how Storywork can help us understand and
8 improve maternal-infant birth outcomes among
9 Native people.
10 So, this is a paper I published. I had
11 some co-authors on how Story is used for
12 healthcare research. Following here are the three
13 key objectives for today's talk. Basically, we're
14 going to talk about history. We're going to talk
15 about adverse childhood experiences with
16 historical trauma and how these theoretical
17 frameworks can be applied to understand indigenous
18 health.
19 Before I begin this presentation, I want
20 to acknowledge the ancestral land which I am
21 standing upon right now. My feet are resting on
22 shared ancestral land and I'm paying homage to

1 these ancestors and memories, but also paying
2 respect to those who are still living here, who
3 were displaced by federal, state, and local
4 policies. I encourage you to find out which
5 travel lands, ancestral lands that you reside one.
6 That equity is justice and fairness are
7 an underlying theme of this presentation. As you
8 listen to the story, please ask yourself at
9 different junctions if justice and fairness are
10 present. Now I can begin.
11 My name is Janelle Palacios. I'm Salish
12 and Kootenai and I grew up on Flathead Indian
13 Reservation in Montana. I've been a nurse-midwife
14 for over ten years, and before becoming a midwife,
15 I collaborated with Native communities to
16 understand teen pregnancy and parenting.
17 I'm past, present at the Native Research
18 Network and it's an indigenous organization that
19 has clinicians, public health researchers, and
20 epidemiologists aimed at improving indigenous
21 health. So, thank you for joining me today.

1 The photo you see right here are of my
2 great grandparents, Olive, and Ernest. They were
3 married in 1926. Both were enrolled members of
4 our tribe and grew up on a reservation. Both
5 attended Indian boarding schools which I'm going
6 to discuss later.
7 I have a high alert warning for this
8 presentation. It's going to cover some materials
9 that may be triggering. I will discuss systemic
10 structural racism, forced sterilization, and
11 genocide.
12 This presentation has done its job if it
13 promotes discomfort and causes tension, providing
14 fuel for growth on an individual level, a team
15 level, and organization, and finally among our
16 larger U.S. culture as we recognize our nation's
17 history.
18 I will use Story as a way to facilitate
19 your knowledge of the importance of history and
20 the effects we have on indigenous health. I want
21 you to know that the principles I am sharing
22 today, the importance of understanding history,

1 background, and life course can be used across
2 different communities, and I would argue essential
3 to really understand health and well-being.
4 To facilitate this understanding, I'm
5 going to weave my family story throughout. My
6 hope is that after today's Storywork you will
7 challenge yourself to consider the importance of
8 history and context as you carry on the work you
9 do.
10 Today I will use the terms indigenous
11 Native, Native American, American Indian
12 interchangeably, and I'm going to limit most of
13 the presentation to the lower forty-eight states.
14 I want you to know that this is not --
15 there are so many parts of indigenous history that
16 I was not able to include in this short period of
17 time and I encourage you to seek more information.
18 I also want you to know that we are a
19 strong people. We're resilient. The fact that we
20 are still here shows that we are resilient despite
21 all the hardships we have faced.

1 Many of us know this. This is why we're
2 here. We're talking about black indigenous women
3 who die at higher rates than white women when
4 they're pregnant or after they give birth. We
5 know that education is not protected, and we also
6 know that as black and indigenous women age, their
7 outcomes are worse.
8 Also, we know that among infants, sudden
9 unexpected infant death syndrome, especially among
10 Native people are the highest. And if you were to
11 look at where we have hotbeds of sudden unexpected
12 infant death, you'll find that in many states
13 where there's a high concentration of Native
14 people you'll find higher rates of SIDS -- SUID,
15 sorry.
16 We should all be familiar with this
17 slide, too, doing the work we do at maternal-child
18 health. This is Dr. Lu's model to explain life
19 course theory as it pertains to racial and ethnic
20 differences.
21 So, in general, white women may
22 experience less assaults over their lifetime and

1 have more protected factors while black and
2 indigenous women are at risk of experiencing more
3 assaults over their life course with fewer
4 protected factors to mitigate the assaults,
5 overall affecting reproductive and perinatal
6 health.
7 This should also be very familiar. This
8 is a famous study that was done in partnership
9 with the CDC and Kaiser Foundation, the Adverse
10 Childhood Experiences, where we found that
11 traumatic childhood experiences and from
12 subsequent research, we understand that as adults,
13 that these traumatic childhoods have resulted in
14 long term negative health effects such as smoking,
15 alcoholism, drug use, suicide attempts,
16 depression, diabetes, obesity, lots of issues.
17 The theory states that as the number of
18 adverse childhood experiences increase, so does
19 the risk for negative health outcomes throughout
20 their lives. This simple, amazing study should be
21 taught, not just among clinicians and experts, but
22 should be taught in schools and in larger, wider

1 community circles. This is just important
2 information to know. I think that if people
3 understood this, there would be more empathy.
4 Adverse childhood experiences have
5 lasting impacts on health and opportunity.
6 Opportunity is the significant factor that is not
7 always discussed, which I will address in this
8 presentation. So, the top QR code is a citation
9 for this figure, held at the CDC, and the bottom
10 QR code is for you to take your own adverse
11 childhood experience quiz via NPR's website.
12 Evidence suggests that ACE's, Adverse
13 Childhood Experiences, affect fertility. So, this
14 study published in 2019 found that among 2,700
15 women in the UK, psychosocial adversity in
16 childhood is a potential risk factor for single
17 and recurrent pregnancy miscarriages.
18 How do we apply these concepts to Native
19 families? While in graduate school I tried to
20 unify historical trauma theory and the theoretical
21 framing known at the time by weathering from
22 Arline Geronimus, who talked about allostasis,

1 which was really trying to get out what Michael Lu
2 was also sharing in the life course work.
3 And through Dr. Maria Yellow Horse Brave
4 Heart's extensive work on historical trauma, it
5 helps us understand that historical trauma is the
6 cumulative multi-generational collective
7 experience of emotional and psychological injury
8 to communities and their decedents.
9 These are traumas experienced by a
10 specific culture, racial or ethnic group. It is
11 related to major events that oppressed a
12 particular group of people, including traumatic
13 community-wide events like slavery, the Holocaust,
14 forced migration, and violent colonization of
15 Native Americans.
16 The genesis of historical trauma comes
17 from work directly with Holocaust survivors and
18 their children.
19 Historical trauma responses result in the
20 manifestation of emotions and actions, the
21 behaviors that stem from this perceived trauma.

1 So, this is my twenty-year-old something
2 rendition combining theories that discuss current
3 lived conditions backgrounded by one's collective
4 community and family history. As the first few
5 generations of a particular victimized group
6 experience traumatic events, responses were passed
7 on to future generations. And today we now
8 understand that trauma can leave a chemical mark
9 on a person's genes, which can be then passed down
10 to future generations.
11 This mark doesn't cause a genetic
12 mutation, but it does alter the mechanism by which
13 the gene is expressed. This alteration is not
14 genetic but epigenetic.
15 My work was trying to understand Native
16 women's health in context by history of traumatic
17 events and also dealing with living and
18 opportunities available.
19 When I first published this study, I
20 tried to talk about epigenetics, and I had to
21 retract it since there was just not enough

1 evidence. And I'm glad to say today we have much
2 more understanding of this.
3 Now, what is historical trauma? As I
4 discussed, Dr. Brave Heart defined historical
5 trauma as the cumulative multi-generational
6 collective experience of emotional and
7 psychological injury in communities and decedents.
8 And in this collective experience across
9 generations among Native people, I'm going to be
10 speaking about general indigenous history, so not
11 specific to just one group of people but just in
12 general in the United States as experienced by a
13 collective group such as colonization,
14 assimilation policies, and sterilization.
15 This figure, the authors described a
16 model to understand cumulative health effects,
17 given historical trauma. This model produced by
18 the CDC outlines methods in which ACE's, those
19 adverse childhood experiences, influence health
20 and well-being throughout the life span. And I
21 was really happy to see that historical trauma was
22 included in this model.

1 So pictured above is the typical flow map
2 when clinicians are reporting on a patient in a
3 healthcare setting. So, a thirty-two-year-old
4 Native American woman at thirty-three weeks
5 gestation and six, seven days, you know, has
6 hypertension and diabetes Type 2, and this person
7 has fetal demise.
8 But this is what these cases look like
9 when you look at the people behind them. These
10 four women are women I know, my grandmother, my
11 great aunt, my mother, and my best friend,
12 Tashina, for which I have placed my picture to
13 stand in for her.
14 Three of these women were teen mothers
15 and combined these women survived nine pre-term
16 deliveries, two infant deaths, two fetal demises,
17 a core sterilization, suicidal ideation,
18 alcoholism, abuse of violent relationships,
19 countless rapes, near misses in being murdered,
20 poverty, and daily encounter steeped in racism on
21 a reservation that shares land with a known hate
22 group.

1 To receive better care, if you had money,
2 a tank of gas, and reliable transportation, the
3 choice to buy goods and services off-reservation
4 was always prioritized. One of these women chose
5 to drive over 120 miles round trip to deliver her
6 first child for fear of what she would encounter
7 at the local hospital.
8 So, this presentation will discuss each
9 of these women's experiences of maternal-infant
10 morbidity, mortality in terms of their life
11 context, not their race, but their inherited
12 histories, their launch in life, and the
13 opportunities open to them in the life they lived.
14 Their stories help frame our understanding of how
15 powerful the background is really.
16 So, I'm going to start with history. For
17 many of you, this will be your first in-depth
18 contact with general Native history. Do not feel
19 embarrassed. These histories are not widely
20 taught in our public education system.
21 Have you ever wondered what the world
22 looked like before settlers arrived? Here is a

1 map created by Victor Temprano, a Canadian artist,
2 and he said I feel that Western maps of Indigenous
3 nations are inherently colonial. They delegate
4 power according to imposed borders that don't
5 really exist in many nations throughout history.
6 When I look at this map a few things
7 stick out for me personally. First, I see that
8 indigenous groups moved, and they occupied vast
9 territories and they shared these territories,
10 they coexisted.
11 But also, this map exposes some lifelong
12 internalized prejudice. Growing up in
13 Northwestern Montana, where some of my tribe, the
14 Kootenai people, lived across the Canadian border,
15 as parts of Canada were traditional lands that the
16 Kootenai people lived on.
17 I always considered my cousins to the
18 north family, but I was surrounded by messages
19 that those from the south such as Mexico, were
20 not. Where, in fact, very much a part of my
21 epigenous family, and the border crosses us.

1 So, when thinking back to the four women
2 at the beginning of the presentation, how can we
3 understand their maternal-infant outcomes in
4 context of their history, and does it matter? I
5 would say it does.
6 So before contact in 1492, the estimated
7 conservative size of the indigenous population was
8 roughly about sixty million people, while in
9 Europe it was between seventy and eighty million
10 people.
11 By 1600, the indigenous population lost
12 56 million people due to diseases brought across
13 from Europe. So, in a hundred and ten years,
14 we've lost ten percent of the global population.
15 This is the largest human known mortality event by
16 proportion.
17 So, for comparison, eighty million people
18 died in World War II, but that only accounted for
19 three percent of global population lost.
20 As westward expansion continued and
21 treaty-making was happening, the indigenous people
22 were removed from their homelands and pushed

1 farther west. This slide shows the largest
2 organized forced removal by the U.S. government in
3 1830 called the Indian Removal Act, which was
4 supported by President Andrew Jackson and passed
5 by Congress. Over one hundred thousand men,
6 women, infants, and children were given a marshal
7 escort, traversing over five thousand miles across
8 land and water to the Oklahoma territory and
9 forced onto reservations.
10 This death march was later named the
11 Trail of Tears, and it's estimated that between
12 four and eight thousand women, men, infants, and
13 children died of cold, hunger, and disease during
14 this winter death march.
15 Prior to 1871, the U.S. government had
16 treaties with different tribes. And this is
17 really important. It is because we have treaties
18 that a number of tribes today have been able to
19 maintain a special status with the federal
20 government.
21 So, in other words, in exchange for
22 giving up our lands, ceding our lands, tribes were

1 given smaller plots of lands, reservations, access
2 to health care and education.
3 Again, because my ancestors ceded our
4 ancestral land and agreed to give up large
5 portions of our traditional lands, my ancestors
6 were relegated to reservations, imprisoned there
7 oftentimes for one generation or more, and given
8 meager resources to live off of.
9 The alternative was to fight and die and
10 some tribes did this, and they forfeited their
11 federal recognition.
12 On this slide, you see the traditional
13 lands of the Sioux, also known as the Nakota,
14 Dakota, and Lakota people. Originally in green,
15 you can see their traditional lands across the
16 Midwest, and currently, the reservations are much
17 smaller in a few states, predominantly in North
18 Dakota, South Dakota, Minnesota, and Nebraska.
19 It's a big change.
20 This is just a visual representation
21 showing you that land that was ceded or forcibly

1 taken from the indigenous people. In a span of
2 sixty years, most of the land was gone.
3 This is what it looks like today, the
4 purple highlighting federally recognized tribes
5 with reservations and the tiny green speckles are
6 those Indian reservations which their state only
7 recognize, and they do not have special nation-to-
8 nation status with the federal government.
9 Next, let's talk about food sources.
10 Bison were a traditional major food source for
11 many Native people. And as you can see here,
12 there were two types of Bison, which I did not
13 know. The Wood Bison which are largely extinct
14 now, and the Plains Bison. In a span of fifty
15 years, from 1840 to 1880, the bison in North
16 American dropped from forty million to less than
17 four hundred thousand.
18 And again, in nine years that number
19 dropped to five hundred and forty=one free-ranging
20 buffalo in the world with about only three hundred
21 roaming in the U.S.

1 Bison were directly targeted for sport,
2 food, and to sell their hides. But the dramatic
3 shift in bison population is largely attributed to
4 the government policies aimed at eliminating this
5 food source to weaken any uprisings, preventing
6 tribes to unify and live together in large
7 numbers.
8 The sharp decline in available food
9 sources also created widespread starvation and the
10 government was able to more easily move tribes
11 onto reservations, thus controlling food
12 resources.
13 This painting is named American Progress,
14 aptly named as this perfectly represents the
15 Western view of progress.
16 Lady Progress is seen moving from the
17 enlightened and civilized east towards the dark,
18 stormy, and wild west, chasing Indians and
19 buffalos to make way for American progress.
20 To facilitate the simulation the
21 government enacted the Dawes Act of 1887. This
22 gave male heads of households individual parcels

1 of land to farm, but also allowed tribes for the
2 first time to outright sell their land from
3 reservation to non-Indian.
4 So, this shift in property ownership and
5 ability to sell reservation land had disastrous
6 results where many -- much tribal land was lost
7 and reversed in the 1930s by this policy, the
8 Dawes Act was revered in the 1930s by the Indian
9 New Deal.
10 So, in general, the Dawes Act prompted
11 the concept of western expansion by promising land
12 in exchange for settlement, but the Act was
13 primarily an attempt to handle increasing
14 conflicts, separate Native people from tribal
15 lands, and also try to force them to culturally
16 accepting a Western model of land ownership.
17 And some tribes historically farmed, but
18 many did not, and the concept of owning a piece of
19 land was so much foreign, especially that an
20 Indian could own -- that an individual could own
21 land and not share with the community.

1 Additionally, the Dawes Act allowed the
2 government to sell and give away land to settlers.
3 This is an actual ad posted in 1911 by the U.S.
4 Department of Interior advertising reservation
5 Indian land.
6 And if you look really closely, it was
7 published in 1911, but in 1910 they have the
8 approximate acres and average price per acre for
9 Oklahoma, Oregon, South Dakota as selling points
10 for 1911. So, this slide represents the after-
11 effect of the Dawes Act. This is my tribe.
12 So along with this act was the ability
13 for both the federal government to sell or give
14 away lands to settlers. This is essentially what
15 happened on my reservation in Montana. My
16 reservation is a patchwork quilt of land actually
17 held by my tribe versus non-tribal settlers. The
18 influx of Western settlers is also why the
19 educational board and economic growth is heavily
20 influenced by it, if not largely controlled by
21 non-Natives.

1 So, the green land is land held by my
2 tribe as largely forested land. The yellow land
3 is typically non-indigenous, it's non-Indian owned
4 land, and it's typically farmland and also land
5 around towns.
6 What year was religious freedom founded
7 in this country? Some would answer 1620 with the
8 Mayflower. Others might say 1791 with the First
9 Amendment. But when did Native religious freedom
10 actually happen? 1978 the American Indian
11 Religious Freedom Act was passed.
12 So, the above image on the right is of a
13 ghost dance, a religious ritual to drive away
14 invading settlers and restore the indigenous
15 people to their ancestral lands and way of life.
16 This dance was banned as the government believed
17 it would renew Native militancy and lead to
18 violent rebellions.
19 On December 29th, 1890, one of the final
20 chapters of America's long Indian wars, the U.S.
21 Calvary killed 146 Sioux at Wounded Knee on the
22 Pine Ridge Reservation in South Dakota in response

1 to stopping the ghost dance from happening and
2 spreading.
3 Historians speculate that double the
4 number of Sioux people were killed and half
5 speculated to be women, infants, and children, but
6 their bodies were largely taken by family members
7 for burial. The U.S. 7th Calvary lost twenty-five
8 men. This is a mass grave following the massacre
9 at Wounded Knee.
10 In this painting done by Oscar Howe, a
11 Dakota man, had personal (inaudible) massacre,
12 recalling how his own grandmother's stories about
13 being shot in the hand by white soldiers. This
14 painting was actually purchased as gift for
15 President Dwight D. Eisenhower. It's rarely seen.
16 Next, I'm going to talk about boarding
17 school experiences. Not long after reservations
18 were formed and indigenous people forced onto
19 them, boarding schools were created. Oftentimes
20 these were religious-based boarding schools that
21 were federally funded to educate children, and one
22 of the oldest Indian boarding schools was built in

1 1879, the Carlisle Indian School located in
2 Carlisle, Pennsylvania, ran by General Richard
3 Henry Pratt, a civilian war veteran.
4 His motto was to kill the Indian save the
5 man. General Pratt believed that Indian savages
6 were equal to Europeans but that it was necessary
7 to kill the savage, strip him of his language,
8 culture, and family, and made forces with corporal
9 punishment.
10 Students were forced to cut their hair,
11 change them name, stop speaking Native languages
12 and convert to Christianity. (Inaudible)
13 including corporal punishment and solitary
14 confinement for any infraction of these rules.
15 The approach was ultimately used by
16 hundreds of other Native American boarding
17 schools, some operated by the government and many
18 more operate by churches. Carlisle was a model
19 Indian boarding school for its time and became a
20 template for federally funded Indian boarding
21 schools of which twenty-six (inaudible) and spread
22 across the country. Over ten thousand Indian

1 children were held hostage here, representing over
2 one hundred and forty unique tribes with their own
3 cultures and languages.
4 It was customary for children to be sent
5 far away from their homes to deter them from
6 escaping. Children were stolen from their
7 families as young as age four and held against
8 their will and the family's will until they turned
9 eighteen or nineteen.
10 In the summer months, children either
11 stayed at the boarding school or were hired out to
12 surrounding families in an ongoing effort to
13 detribalize the youth.
14 These photos are of Arapaho children when
15 they entered the boarding school on the left and
16 then as they were beginning their assimilation on
17 the right. Oftentimes General Pratt had before
18 and after photos taken to document successful
19 assimilation
20 This is Tom Tramene (phonetic), a young
21 Navajo teen who was captured and taken to Carlisle
22 in 1882. The side-by-side comparison is of Tom's

1 first day in 1882 and three years later in 1885,
2 publicity, propaganda. These photos documented
3 the successful assimilation of a savage.
4 This is a photo of my great grandfather,
5 Ernest. He attended Haskell Indian Boarding
6 School until he enlisted in World War I.
7 As time went on sending children far away
8 to boarding schools proved expensive and
9 challenging. Challenging as Indian kids run away
10 did not make a great headline. So Indian boarding
11 schools were built on reservations.
12 While these are not photos of my
13 reservation, there are nuns offering the St.
14 Ignatius Mission boarding school which was started
15 in 1864.
16 In 2011 forty-five men and women stepped
17 forward with allegations of sexual, physical, and
18 emotional abuse from nuns and priests with some of
19 the victims were as young as age five.
20 So again, boarding schools, the Carlisle
21 Indian Boarding School was established in 1879.
22 Its policies were (inaudible). There was rampant

1 abuse. It detracted from parental modeling, and
2 these were traumatic experiences ultimately
3 leading to cultural destruction.
4 Today the U.S. Bureau of Indian Education
5 still operates four off-reservation boarding
6 schools. These schools aim to provide a quality
7 education to students from across Indian country
8 and empower indigenous youth to better themselves
9 and their communities.
10 So, the top link is the digital resource
11 center for more photos and information from
12 Carlisle Indian Board School. And then the bottom
13 link is actually to read stories from actual
14 survivors from Carlisle Indian Boarding School,
15 from the survivors and their family members.
16 As young as age four. Look at the little
17 kids on the front row, trapped for fifteen years.
18 The boarding school is not just a way to
19 assimilate the future generation of Indian youth,
20 it was also a way to terrorize them and destroy
21 healthy family patterns.

1 Children grew up without their family and
2 extended family, without healthy role models for
3 what a functioning family looks like. Surviving -
4 - survivors of the boarding school only talk about
5 returning to their homes ill-equipped to the
6 skills, language, and culture to function normally
7 and healthily in their community.
8 Over the past thirty years, survivors
9 have come forward, sharing their stories of abuse
10 at the hands of adults in charge of them, but also
11 fellow students, verbal abuse, sexual abuse,
12 physical abuse, emotional abuse, violence,
13 violence, and more violence.
14 One hundred and eighty-six children's
15 graves are at Carlisle. Survivors have shared
16 their collective memories of murder and neglect.
17 Children who tried to escape were hunted and
18 sometimes killed.
19 When reading historical documents, as I
20 did, it's astounding to see the number of children
21 who died while out on an outing, and you can read
22 these documents for yourself.

1 Over four thousand children's bodies have
2 been found in unmarked graves across residential
3 boarding schools throughout the U.S. and Canada.
4 July of this year, two hundred and fifteen
5 children's bodies were found at the Kamloops
6 Indian Residential Canadian Boarding School just
7 north of Montana, with some of the youngest bodies
8 found were three years of age. Two hundred and
9 fifteen children, some not even school age.
10 Secretary of the Interior, Deb Haaland,
11 announced that a comprehensive review of the
12 Federal Boarding School policies would be
13 conducted via the Federal Indian Boarding School
14 Initiative with preliminary reports expected April
15 2022.
16 Someone argued that as Indian Boarding
17 Schools fell out of favor, placing Native children
18 in adoption increasingly became the way in which
19 children were assimilated and cultural destruction
20 continued.
21 Indian identity is complex and a hotly
22 contested issue, both within tribes and on the

1 state and federal levels. And one area where
2 Indian identity has life-changing implications is
3 when you look at children being adopted.
4 In 2015 data across the U.S. found that
5 Native children are overrepresented than any other
6 ethnic identity within the foster care adoption
7 population. For everyone white child, there are
8 about three Native children in foster care.
9 One last method to deal with the Indian
10 problem was to assimilate the 1950's policy called
11 the Indian Relocation Act. This time to
12 assimilate Natives, the government took to
13 terminating reservations by encouraging whole
14 families to move to cities. Over two hundred
15 thousand people were displaced or relocated to
16 cities like New York, LA, Minneapolis, Chicago,
17 Seattle, Oakland.
18 This, too, proved disastrous leaving
19 entire families stranded in cities without proper
20 support and lack of support to return to the
21 communities. And some tribes completely

1 dissolved. Today, seven out of ten Native people
2 live in urban areas.
3 So roughly seven million people identify
4 as Native, which is roughly about two percent of
5 the U.S. population. There are five hundred and
6 seventy-four federally recognized tribes in the
7 U.S.
8 In 2017 less than one percent of all U.S.
9 households were owned by Natives compared to
10 sixty--three percent of white Americans. And in
11 the same year, the median household income for
12 Natives was about forty thousand versus fifty-
13 seven thousand for the general population, and
14 about twenty-six percent of Natives live in
15 poverty versus fourteen percent of the nation as a
16 whole.
17 The average poverty rate on a reservation
18 can be ranging from twenty-five to sixty-four
19 percent, depending upon the reservation. And for
20 your reference, during the great depression, the
21 poverty rate was about twenty-five percent. And
22 during the pandemic that we're currently in, the

1 August of 2020, the highest rate of poverty was
2 seventeen-point three percent.
3 Collecting data on indigenous health is
4 challenging and sparse, but in a CDC review from
5 2009 to 2011, we know that the top three killers
6 among Native adults include heart disease, cancer,
7 and unintentional injuries. Life expectancy is
8 about five-and-a-half years less than the U.S.
9 general population.
10 And the top three killers for Native
11 women ages one through 19, unintentional injuries,
12 suicide, and homicide. Violent deaths,
13 unintentional injuries, homicide, and suicide
14 account for seventy-five percent of all mortality
15 in the second decade of life for Native people.
16 Native Americans are the only ethnic
17 group in the U.S. that still require tedious
18 record-keeping to prove their identity. To
19 determine who was eligible for land, the federal
20 government required each tribe to create
21 requirements to determine tribal membership.

1 Keep in mind that tribes traditionally
2 have dynamic values regarding identity. Their
3 first were trappers and people historically
4 captured during wartime that were given equal
5 travel status and membership.
6 So, the Western idea of linking blood
7 quantum to identity, much as one would view the
8 pedigree of a dog or a horse was foreign.
9 Nevertheless, this was firmly supported by the
10 U.S. government, which was supported at least one-
11 quarter degree of that particular tribe's blood to
12 be enrolled.
13 As you can imagine, data collection among
14 Native people is fraught with problems. What we
15 really are trying to measure is experience, not
16 race, and Native communities with the dynamic-
17 colored population, light featured Native people
18 are at risk of experiencing similar historical
19 trauma and ACE's, but when their data -- but their
20 data may not be captured due to data collection
21 flaws.

1 So American Indian identity and tribal
2 membership is sensitive. The indigenous people
3 who need a degree of Indian blood did not have --
4 did not have enough of any one tribe are not
5 enrolled. And then there are those who grew up on
6 the community with their culture, living the same
7 lives, experiencing the same obstacles but fall
8 short of blood quantum required for membership.
9 ` So this paper captured Native
10 Americans -- the issues of data collection among
11 Native Americans when we look at identity.
12 And rather than asking someone how much
13 Indian are your, a better question would be, where
14 are your people from, or which tribe are you?
15 But why is membership important? Because
16 remember, membership is tied to access to
17 resources like land. This is a copy of a 1936
18 Indian Census roll which shows my great
19 grandmother, Agnus Irvine Dupuie, was a member of
20 the Flathead tribe, and she had a lot named
21 1010670.

1 This photo shows newly built HUD homes on
2 my reservation. You're not seeing HUD housing in
3 the neighborhood I grew up in. But living on
4 reservations has been likened to living in a
5 developing country. Over three hundred thousand
6 Native people are under-housed and are homeless.
7 Over thirty percent of reservation housing is
8 overcrowded, while only fifty percent of the same
9 housing is connected to sanitation.
10 One in ten families have stable and
11 reliable internet connection on reservations. One
12 in ten families have unreliable sources of clean,
13 freshwater, and one in three reservation-based
14 families live without plumbing.
15 Another resource is access to the
16 commodes. This is from the food distribution
17 program on Indian reservations, and these are
18 actually also commodities that are given out
19 throughout the military. Beef with juices. A
20 five-pound block of mild cheddar cheese, peanut
21 butter. I grew up eating this food. It was a
22 stable in my household. And as food became scarce

1 near the end of the month, meals became creative.
2 My favorite was a spoonful of peanut butter dipped
3 in crumpled uncooked spaghetti sticks.
4 So, imagine what a high fat, high
5 protein, high sugar diet does to a body. Well, we
6 have Indian Health Service to help us.
7 In the 1950s the Indian Health Service
8 was created. Indian Health Service, or IHS, is
9 split into twelve service areas. The largest IHS
10 service area is typically Oklahoma, with roughly
11 about four hundred and twenty-seven thousand
12 people. Unfortunately, it was at an IHS service
13 site that a mass sterilization campaign was
14 carried out upon Native women.
15 In 1972 a woman entered a Los Angeles
16 clinic requesting a lung transplant. She relayed
17 a story of having her uterus taken out at an IHS
18 facility.
19 Similarly, two fifteen-year-old girls
20 went into an IHS hospital in Montana for
21 appendectomies and were discharged with tubal

1 ligations. Neither had been consented nor their
2 parents.
3 After uncovering a number of antidotal
4 incidents an investigation was conducted in 1976
5 by the U.S. General Accountability Office. This
6 investigation only reviewed cases among four of
7 the twelve IHS areas between 1973 to 1976. They
8 uncovered that three thousand four hundred and six
9 women had been sterilized during this three-year
10 time period. I note that thirty-six cases
11 involved women under age twenty=one, as young as
12 age eleven.
13 It's not clear why the investigation did
14 not include all twelve sites, nor why it only
15 included a span of three years. Experts
16 hypothesized that at least twenty-five percent and
17 as much as forty percent of the childbearing
18 population at this time had been sterilized,
19 roughly about seventy thousand women may have been
20 sterilized in this period, while comparatively,
21 the rate of sterilization of white women was about
22 fifteen percent.

1 Taking a woman's future reproductive
2 capability without consent is an egregious human
3 rights violation. And when targeting a specific
4 population, it's considered genocide. While some
5 sterilizations were desired, the massive
6 sterilization campaign against this population
7 started in the 1930s, spilling over into the
8 1980s, spanning fifty years.
9 Some boarding school survivors have come
10 forward with their own stories of forced
11 sterilization before leaving school.
12 But maybe we should extend this time
13 today for it continues as my cousins on the border
14 are being held captive, abused, and traumatized
15 and their reproductive futures have been taken
16 from them.
17 Native American women and girls face a
18 high chance that they will experience violence and
19 possibly be abducted and murdered. in 2016 alone,
20 five thousand seven hundred and twelve indigenous
21 women and girls were reported murdered or missing.
22 Eighty-four percent of indigenous women have

1 experienced violence in their lifetime. Fifty-six
2 percent have experienced sexual violence, and on
3 some reservations, indigenous women are murdered
4 ten times the national average. Murder is the
5 third leading cause of death for indigenous women.
6 Ninety-six percent of rapes are
7 perpetrated by non-Native men, but non-Native
8 offenders are rarely prosecuted on the tribal
9 lands.
10 It is a travesty that any life is lost.
11 And certain Gabby Petito's murder is horrific.
12 But the amount of attention to one girl in itself
13 is a disparity, while little to nothing is shared
14 about black, indigenous women of color, and girls
15 who are being murdered and go missing every day.
16 The most recent contemporary issue
17 Native's face is Covid-19. And this is Abigail
18 Echo-Hawk. She's the director of Seattle's Urban
19 Indian Health Institute. Abigail requested
20 assistance from the local, city, county, state,
21 and federal programs when Covid hit. They simply

1 requested protective equipment, gloves, and masks
2 and they were sent cadaver bags.
3 When we turned in incarceration rates,
4 the highest rates are among people of color. This
5 data is old, it's ten years old but likely remains
6 true today. And when you look at each state's
7 incarceration rate by race and ethnicity, there
8 are several states where Native people, men,
9 women, and children are incarcerated at higher
10 rates than any other ethnicity.
11 This is an example in Montana. So Native
12 people make up about six percent of the general
13 population but compose twenty-two percent of the
14 prison and jail population.
15 This happened a little over a year ago.
16 Women were racially profiled and then their
17 addresses were checked to see if they lived on or
18 near a reservation. No matter if the tribe had
19 not had one case of Covid, the newborn was
20 separated from its mother by hospital policies
21 that still have not been clearly shared.

1 This is going to be the last slide. And
2 then this happened. This is triggering.
3 From a recent published review, the top
4 three causes of indigenous maternal mortality are
5 hemorrhage, cardiomyopathies, and hypertensive
6 disorders. Again, these known factors are just
7 known facilitators in maternal mortality but
8 likely reflect these women's lives.
9 There's too little data to determine if
10 homicide and suicide are large factors, but my
11 suspicion is that it will vary depending on where
12 you draw your data from.
13 Finally, in this report, substance use
14 was not reported as a factor. So, these are the
15 general themes for risks for preterm birth among
16 Native women. Again, there are implications from
17 history and current conditions. And access to
18 healthcare has consistently been a barrier.
19 A recent study published found that
20 Native women travel significantly farther to
21 access OB care and in particular more complex OB

1 care than white women living in similarly rural
2 areas.
3 Native women are twenty times more likely
4 to give birth at a facility that lacks an OB unit
5 compared to white women.
6 A final word on trauma -- I'm going to
7 skip this line. The effects of historical trauma
8 and adverse health experiences along my life
9 course can be manifested in many ways. And trauma
10 is ongoing. It seems to not quite end.
11 Among Natives, it has included the trauma
12 has facilitated a breakdown of traditional Native
13 family values, alcohol, substance use as self-
14 medication, depression, anxiety, suicide ideation
15 and suicide attempts, child abuse, neglect and
16 domestic violence, post-traumatic stress disorder,
17 general loss of meaning and sense of hope and
18 self-hatred.
19 While this is a challenging presentation
20 to hear, I want you to know that these stories
21 must be heard and understood in order to

1 effectively address the health disparities among
2 Native people.
3 I want to thank you for your
4 participation and openness to listening and
5 learning more about indigenous health history.
6 And with this, again, my hope is that you will
7 take this history as an example of how it can be
8 applied to other populations.
9 It's knowing -- it's being like a global
10 citizen, a global -- someone who is aware of
11 history to help understand other people's
12 experiences. And when we understand history and
13 experiences, we can try to make changes for the
14 betterment, which is why I've advocated for large-
15 scale changes. Thank you.
16 I will now pass the baton to Dr. Susan
17 Stemmler. And I just want to share with you all
18 that Dr. Stemmler is a -- one moment. I apologize
19 for this, my screen is not working on my end, so
20 Susan, I will -- Dr. Stemmler, I would like you to
21 go ahead and present yourself so that we don't
22 lose any time. Thank you.

1 Dr. Stemmler, are you there? I'll go
2 ahead. Dr. Stemmler is a nurse-midwife and a
3 researcher. She's a member of the Choctaw Nation
4 of Oklahoma. She is a certified nurse-midwife,
5 and she is retired faculty of California State
6 University of Dominguez Hills School of Nursing.
7 Dr. Stemmler completed her undergraduate
8 work in nursing at the University of Oklahoma-
9 Newman, and she earned her MPH and Ph.D. in
10 nursing at UCLA. She completed a post-op
11 fellowship at UCLA School of Medicine, Department
12 of Family Medicine Center for Behavioral Addiction
13 Medicine.
14 Dr. Stemmler's research interests involve
15 women's health, substance use, American Indian
16 health. She has focused her attention to
17 developing primarily clinical interventions for
18 use of methamphetamine, using pregnant mothers.
19 As a woman's healthcare specialist, she has worked
20 as a clinician and an administrator of community
21 clinics in Los Angeles County. And she has acted

1 as a maternal-child health consultant in
2 international studies. Welcome, Dr. Stemmler.
3 VANESSA LEE: I know Dr. Stemmler was on
4 before, but it doesn't appear she's on now. Would
5 it be possible for Dr. Bane Frizzell to go first
6 while we figure out where Dr. Stemmler went?
7 JANELLE PALACIOS: Yes, thank you for
8 letting me know. Dr. Linda Bane Frizzell, if
9 you're there, you're welcome to go ahead and start
10 your presentation.
11 LINDA BANE FRIZZELL: Okay, commonly
12 pronounced Frizzell, but I understand. Okay, I'm
13 going to share a screen. Let me see if I can get
14 my PowerPoint pulled up. Okay, can people see
15 that?
16 ED EHLINGER: Yes, we can.
17 LINDA BANE FRIZZELL: Okay, I'm going to
18 go into presentation mode, so it shows a little
19 bit bigger.
20 How does that work for you, okay? I see
21 heads nodding and that. Okay. It's really hard
22 to cram all the information I'd really like to

1 share with you into this short time period but
2 learning from my students -- I've been at the
3 University of Minnesota going on six years now --
4 the information I'll share is necessary for them
5 to build a foundation so that they can improve
6 their education and understanding of how things
7 are in Indian country.
8 So, with that in mind, I have general
9 comments to make to ground people. I note there
10 are sixty-nine people who are participating now.
11 I'm not sure of what their background is, but
12 we'll try and help them out here.
13 We also, at the University of Minnesota
14 are squatting on Dakota land. So, the
15 acknowledgment is, we acknowledge that we are
16 located on Dakota land. We recognize a vast
17 amount of indigenous knowledge this land has seen
18 and encourage everyone to be respectful of the
19 distinctive and permanent relationship that exists
20 between the Dakota people and their traditional
21 territories.

1 We also like to pay respect to the
2 elders, both present and past, to allow us to be
3 here today. So as sovereign nations, tribes are
4 responsible for the overall health and well-being
5 of their members, along with the land,
6 environment, and so on.
7 And tribes are becoming increasingly more
8 interested in building their infrastructures to do
9 a variety of businesses in relation to what their
10 constituency would like.
11 So, the first slide is kind of an
12 overview, but it is, at least from my opinion,
13 really necessary to learn the history.
14 Quick example, I had a student several
15 years ago whose third-grade daughter, their class
16 was celebrating Heritage Week, and so whenever it
17 came to her daughter's turn, she started off and
18 said, "Well, I'm an American Indian."
19 The teacher stopped her and said oh no,
20 there aren't anymore. And so similar reactions I
21 see around the country like I say, I've been doing
22 national policy for about thirty years now, that

1 explains a lot. So, it's really a sad situation
2 that things like that are believed.
3 And we -- I also attached -- I don't know
4 if it's been put out for the public, but I sent
5 along an American Indian health and wellness model
6 that a group of us worked and it is finally
7 finalized by the National Indian Health Board in
8 2016, but it talks about, you know, everything
9 that public health involves.
10 So many times, if you ask anybody on the
11 street, well, how is your public health, they'll
12 say okay, well, I had my physical yesterday and I
13 got my mammogram. It's like no, there's things
14 like finances, housing. And sadly, whenever I had
15 to buy a house in Minneapolis because I lived four
16 hours north, where I'm happily at right now, I got
17 redlined.
18 I told the realtor over and over again, I
19 said -- because I was working in North Dakota --
20 no I don't vote there, I vote Minnesota. But once
21 it hit the fan and my lawyer friends tell me, that
22 that is a common practice. All people that have

1 addresses within reservation boundaries get
2 redlined. So just another form of discrimination.
3 So, I'm going to -- some of this will be
4 a little bit repetitive after that super
5 presentation that we had previously, but I'd like
6 to ground everybody in basically how the thought
7 process works from my point of view.
8 So as mentioned whenever Columbus
9 arrived, who knew how many -- it's just alleged
10 ten million people, but by the 1850's the
11 population had decreased to a quarter of a
12 million, from ten million to a quarter.
13 And the primary causes for decline were
14 foreign diseases, which we're certainly
15 experiencing right now, starvation, and
16 specifically extermination.
17 The first governor of Minnesota, Governor
18 Ramsey, actually put a bounty on our ancestors'
19 heads. And I just can't even understand that
20 thought process, but that's what the history tells
21 us.

1 And we are one of the faster-growing
2 segments of the U.S. population. There was just a
3 recent document that came out where they changed
4 the termination. On the census data, it will
5 state American Indian loan. I think the
6 terminology is goofy anyhow, loan what?
7 But anyhow, multiracial, and then it asks
8 for ethnicity. And now is including indigenous
9 people like people from the Incas or Mayans,
10 people that identify as indigenous, they're
11 counting them in with the American Indians and
12 Alaskan Natives, and the result of that is that
13 our group, a conglomerate called indigenous
14 people, represents the most populated racial group
15 in the country. So that's interesting. I'm still
16 trying to get that figured out in my head.
17 So as noted for travel governance, there
18 are five hundred and seventy-five federally
19 recognized tribes and approximately seventy-four
20 states recognized. also noted that there's not a
21 lot of advantage to be in a state-recognized

1 tribe, although it believes they did that just to
2 do what they can do.
3 Tribes literally fight. For everybody to
4 recognize, it is a political fight. There's no
5 logic to it, it's jumping hoops that in my opinion
6 are quite insulting.
7 And historically before, you know, timely
8 immemorial, Indian people survived either
9 matriarchal, patriarchal, spiritual, or conquered,
10 and that's how we're here today.
11 In the seventies, the mid-seventies, the
12 Public Law 93-638 was introduced which required
13 tribes to have a constitution. Who knows if they
14 had one before, and another change is that
15 directly represents our federal model now? And
16 so, what I like to share with my classes very
17 quietly is, well, you see how well that's working,
18 and that's all I'm going to say about it. I tend
19 to get myself in trouble, but anyhow. So
20 basically, millennia of cultural practices were
21 discarded.

1 And another example of that, I'm Eastern
2 Cherokee and Lakota. My Cherokee ancestors, we
3 had developed a total complete judicial system, an
4 advanced university system. And what the federal
5 government did is they came and kind of burned
6 them down. I mean, they did burn them down and
7 threw it away because you know, we're not supposed
8 to know stuff, you know. We're a domestic-
9 dependent nation.
10 So ironically, whenever the billings were
11 reestablished, it was kind of like a mirror of
12 what the Cherokee had already done. So that's
13 just a story I like to share.
14 And it's hard for students to understand
15 that each and every one of the five hundred and
16 seventy-four federally recognized tribes has their
17 own constitution. So, I'm asked by students,
18 well, how many do similar things or do things
19 alike. I'm like, you know, I can't answer that
20 because they're individual.
21 Now, it might appear on the surface that
22 they're doing similar things, but actually, each

1 tribe is their own ethnicity if you think about
2 it.
3 And so, one of the issues over the years
4 that have been detailed to reservations that are
5 in election mode and been detailed to folks that
6 elect every year, it is chaos. And the tribes
7 seem to settle down a little bit more. But once
8 again, it's in their constitution, that's what
9 their constituents agreed to.
10 The hard thing for people to understand,
11 I know Ed, you've heard this a zillion times from
12 the Minnesota tribes, but a government-to-
13 government relationship with the federal
14 government, it is hard for people to grasp. And
15 that's necessary because we are -- we are
16 governments. We do have elected people. And we
17 do have policies and procedures and all the things
18 that any other government would have.
19 And so, with that, it's really important
20 for people to understand, American Indians and
21 Alaskan Natives are identified as a political
22 group, not a racial group. And that's important

1 because we have the ability then to have laws that
2 more directly meet the needs of our people.
3 I've been in D.C. before working on
4 whatever program and people will come in and visit
5 with us and we'll tell them what they're doing and
6 they go well, you can't do that, that's
7 discrimination. I go no, we are a political
8 group.
9 And so, if you look at the current Indian
10 law, it's quite evident to why it's necessary to
11 be declared that.
12 One thing that -- another thing that
13 people have a hard time understanding is tribal
14 governments are not governed by states. You have
15 a lot of collaboration that goes on throughout the
16 country for tribal governments that choose to work
17 with the state, but they're not required to.
18 As a matter of fact, I was a writer on
19 the Indian Health Care Improvement Act. We
20 actually established a -- it's a pseudo national
21 license for our health providers. So now whenever
22 we do tele-med and it's like we don't have to

1 credential because our personnel are nationally
2 certified and that makes a big difference, because
3 that's very costly for the private sector to do.
4 And understanding that oftentimes
5 Minnesota, we have physical boundaries, and Red
6 Lake, and Navajo are the only two closed
7 reservations in the country, but they have gates
8 on the highway, and they can close them whenever
9 they choose to. People within have land that they
10 use, but it doesn't -- they don't have ownership
11 of it.
12 The reservation I live, I had to get a
13 patent deed because of all the people that, before
14 we bought it, had been involved.
15 And then the boundaries as mentioned
16 before between Canada and Mexico, and there are
17 laws that we can't use Indian Health Service
18 dollars to treat Canadians. But if I go into a
19 hospital area or health service area in Canada,
20 they would treat me. So, a little bit of bias
21 there.

1 And the big thing that we found, there's
2 a hundred percent of federal dollars that pass
3 through for health services now, and that was a
4 fight into itself. It was in hiatus for about ten
5 years, but we got that through.
6 But what we didn't get through at the
7 same time, the Balanced Budget Act of 1997 was
8 happening, and we had an opportunity, missed it,
9 where we could have applied for direct funding,
10 which is a preference for tribes.
11 Right now, there's fifty different states
12 that have different quote-covered services, and
13 it's a nightmare. And especially in behavioral
14 health and we have begged centers for Medicare and
15 Medicaid to have a core set that would be required
16 that we could use for behavioral health and
17 haven't got it done yet but we're trying.
18 So basically, the legal foundation is the
19 Treaty of Hopewell, actually preceded the
20 constitution. People don't understand that, and
21 so I like to share that, you know, well, we've
22 been here for a while, you know, like you guys

1 come and stole our land, but we've been here and
2 were original.
3 And so, I like to, whenever I do anything
4 I send to the regions, I like to refer to us as
5 First Americans. Of course, in Canada, it's the
6 First Nations.
7 So, in the constitution there is law.
8 The War Department actually ran health services
9 for Indians. It wasn't because they're, you know,
10 protecting the Indians, they didn't want the
11 soldiers to get sick from the Indians, so that was
12 their hypothesis.
13 And the Snyder Act is a one-pager, but it
14 allowed Congress to appropriate dollars to the
15 Indian Health Service. And this is discretional.
16 it is not entitlement like Medicare or Medicaid,
17 and there's huge issues of underfunding that goes
18 on with that.
19 So, as I mentioned, Indian Self-
20 Determination Education Act was a big deal,
21 because previous presidents had -- were on a fast
22 track to annihilate or unrecognize tribes, and so

1 there wouldn't have been any tribes. But oddly
2 enough, President Nixon was the president behind
3 that that established that law.
4 Then a year later the Indian Health Care
5 Improvement Act, which we submitted to Congress,
6 it was about five hundred pages on October 6th or
7 9th, 1999, and we were proud. I mean, this was a
8 work all night sort of deal, you know, for us
9 grunts that were working on this, and Congress
10 goes okay, thanks.
11 I'm like, don't you understand. This is
12 a consensus document. My ancestors were just
13 about killed off by the (inaudible) folks, and so
14 there's history here between tribes, and you know,
15 it's just right the way that -- what they want to
16 operate, but no. They were okay, thank you. So,
17 it was I hiatus until the Affordable Care Act, and
18 we got tacked onto that in 2010.
19 And then the thing that tends to burn us,
20 even today, is in the Constitution, and you can
21 see there in the red, we are referred to as
22 domestic dependent nations. To change the

1 Constitution, that's what we'd have to do. I
2 doubt if people would understand why, but that
3 dependent word bites us all the time because, you
4 know, we have to be taken care of and looked after
5 in a dependence mode.
6 And then in the Commerce Act, other -- is
7 specific language. It talks about with foreign
8 nations and among the several states and Indian
9 tribes. So that's kind of the basis where things
10 start, and I've got a whole paper that I wrote on
11 all the law.
12 And I should mention, too, my address and
13 email is on the last slide of this deck and it
14 will be available to everyone.
15 So same photo but a little different
16 highlight on that. We've seen that already. And
17 this is something I made because I was having
18 difficulty for folks at the university to
19 understand what's going on. So, if you look at
20 the top of the page it says United States of
21 America Constitution. Now if you look down
22 there's a line and basically on the right side is

1 federal and on the left side is tribal. And I
2 mentioned that tribes have a constitution and that
3 is directly under the U.S. Constitution.
4 Then you go down to the next yellow
5 highlighted area, protocol is the highest selected
6 person from a tribe, whether it be a governor or
7 principal chief, a chairperson, whatever, is on
8 the same protocol as the president of the United
9 States. People don't understand that.
10 Whenever we have things in D.C. some of
11 the elected officials are able to attend, and one
12 time we got to a bunch of -- I'm going to be
13 derogatory on purpose -- but a bunch of grunts
14 that came in and we had elected leadership there.
15 Well, it pretty much hit the fan. And so, things
16 have changed. They just didn't understand what
17 the protocol was. Somebody should have taught
18 them.
19 And so, if you'll note the disclaimer at
20 the bottom, the left side of the -- what the
21 tribal functions were, they got the council and
22 tribal Court, almost every tribe has that. It

1 isn't in a branch system like what we have on the
2 federal side.
3 And the other thing that -- the last
4 four, I think, governors have done -- in
5 Minnesota, have done either an executive order or
6 a resolution dictating that they -- the state will
7 participate in consultation when asked, just like
8 what the federal law says, but the governors are
9 extending that to the state folks.
10 So, I'm going to quickly explain real
11 quick terminology so whenever people hear it
12 because oftentimes you get acronyms, and nobody
13 explains. But the Indian Health Service is a
14 three-legged stool if you will. And you know, the
15 Reconciliation Act of 93 -- added the 638, which
16 is a common term for self-governance, 93-638, and
17 so the 638, the program, as people will say.
18 And then in the Indian Health Care
19 Improvement Act, we put all the urban programs
20 into Title V. Made it a little easier to read.
21 And most of the urban programs are federally
22 qualify health center designated, and all of the

1 tribes in the country have an automatic HIPSA
2 designation. And I don't have time to go into why
3 I'm a little concerned about that, but it's being
4 able to pick highly qualified, not what's left
5 over from the score that you have.
6 So federally recognized tribes and tribal
7 organizations. People get confused. If it's an
8 Indian organization, that's fine. But the law
9 says to get the all-inclusive, it's federally
10 recognized tribes and tribal organizations
11 specifically. So tribal is a sanctioned
12 organization from sometimes multiple tribes that
13 work together.
14 Then lastly, the Indian Health Program
15 consists of thirty-five non-profit programs
16 nationwide. The Minneapolis Indian Health Board
17 was actually the first one to be established. And
18 with the population shift of about eighty percent
19 of our American Indians living in urban areas now,
20 thank goodness it's there.
21 Okay. So more definitive for IHS is it's
22 divided in twelve administrative areas, and I have

1 a picture of that coming up. The federal
2 government doesn't call them hospitals. We all
3 do, but it's referred to as a service unit, so if
4 you hear that term, means a hospital.
5 Same thing for health centers. They're
6 actually satellite clinics, two school clinics or
7 centers, and then urban Indian programs.
8 And I have to tell you, the amount of
9 money that the urban programs get for the IHS is
10 nothing short of totally embarrassing. And so,
11 health boards that have clinics that write grants,
12 they do all sorts of fundraising to meet the needs
13 of the constituents, and so if you look at that
14 all together, the -- it's called and ITU, just
15 because they're lazy and don't want to say the
16 whole thing.
17 So, within tribes and tribal
18 organization, as I mentioned, established by
19 public law 93-638, fifteen hospitals that tribes
20 operate, and where the real influence is the five
21 hundred and thirty-eight satellite clinics, and

1 that really helps. And that includes the hundred
2 and sixty-six Alaska villages.
3 I don't know if you've ever been to
4 Alaska, it's like I don't know how people do it,
5 but they tend to survive.
6 And nine health centers, ten regional use
7 substance abuse treatments centers, and those are
8 operated both by some tribes and the Indian Health
9 Service.
10 Okay. so, a tribe may become an FQHC by
11 writing an attestation statement, that's it. And
12 that's helped some tribes to be able to do
13 billing. Once you get that designation as FQHC,
14 it makes you eligible to bill for Medicaid.
15 And so, the urban programs are funded, as
16 I mentioned, under Title V of the Health Care
17 Improvement Act, but a lot of them receive
18 reimbursement enhanced. I know at the health
19 board in Minneapolis we're getting a little more
20 of an enhanced encounter. But the fairly
21 recognized tribes get the Office and Management
22 Budget flat-rate payment, which if you think about

1 infrastructure of tribes, I mean, a flat rate is
2 like perfect. Otherwise, you got to hire all
3 these people to fill out the necessary paperwork
4 for fee for service. It's called the OMB rate or
5 the all-inclusive rate.
6 Sorry, I can't figure out how to change
7 Aberdeen to Great Plains, but that's -- you saw a
8 picture before about what our twelve Indian Health
9 Service areas are, which is how they tend to work
10 together in policy.
11 And then this slide, you hear over and
12 over again, and I have the data but it's old, and
13 this isn't exactly new, but this is from the
14 Indian Health Service, their data and analysis.
15 And it's just staggering, the amount of money and
16 how we get by with that.
17 But also understand that the Indian
18 Health Service and the tribes and urban folks,
19 it's a pseudo-public health program. I mean, I
20 can get to a number of encounters for prevention
21 services and everything like that where -- and the
22 public has tried to tap into our repository, which

1 is being housed in Albuquerque, and the IHS
2 facilities must submit their progress notes and so
3 on.
4 Tribes actually have the choice -- most
5 of them do because they want the numbers counted.
6 But this is nothing short of embarrassing, and it
7 continues today.
8 So, we got together, and we wrote this
9 huge document, broken promises. We give all of
10 the data, or all the references were for data that
11 we could find through Medicare, Medicaid, and
12 nobody -- Congress just kind of ignores us.
13 Part of the problem is there's only
14 thirty-four states that have tribes in them,
15 federally recognized tribes. So that directly
16 impacts. But the common thing that we say is, oh
17 yeah, well, let's see here, if you look at the
18 charts, you find that the United States Pays less
19 for the Indian Health Service and twice as much
20 for federal prisoners. And you would think that
21 would get attention. Not so far.

1 And this is relatively aged data. And I
2 have a huge problem in I teach a research class at
3 the university, and there's all sorts of issues
4 with Indian data. And there's only a couple. I
5 will rely on the census data. The Indian Health
6 Service data because they actually have the
7 progress notes and things to go -- correspond to
8 that.
9 The big problem is a lot of people will
10 not acknowledge that they're an American Indian if
11 they can pass. A lot. And whenever I was working
12 with the Department of Health, we tried to figure
13 out ways we could capture that. We never did get
14 it figured out.
15 So, this data comes from the Indian
16 Health Service and is always five years in arrears
17 by the time they get everything gathered up, and
18 it comes from a document called Trends, T-r-e-n-d-
19 s, and it's a huge document, but it is valid data.
20 And I have like a couple copies of it I keep in
21 this office here and in Minneapolis.

1 But data is difficult. People don't know
2 oftentimes that it's invalid, and I see a lot of
3 studies, which in my opinion would be a type one
4 error. And if you don't know what that is, it's
5 kind of like a death warrant for the researcher if
6 you submit something with those big of errors.
7 So, you can see how things change. It
8 always stays -- kind of scary if you want my
9 opinion. Homicide changes the most, I think.
10 With some of the pandemic issues with the Covid,
11 it just about annihilated a couple tribes before
12 they got it slowed down.
13 This is from the National Congress of
14 American Indians. It's to give folks kind of a
15 view about telephones. Now, this is a survey that
16 does not entertain the use of cell phones, which
17 has changed a lot. But you can see these
18 determinants, how they affect the overall health.
19 And then the other thing that people
20 don't understand, the experience of a range of
21 violent and traumatic events, serious injury.
22 We've had some kids in a rural town north of here

1 that -- we don't have gangs in Indian country,
2 they're like pseudo gangs or want-to-be gangs.
3 And good grief, this is a female gang, and they
4 beat a blind man on the street in town to death.
5 Don't know why. They couldn't even say why. But
6 I mean, this is awful. And some things are worse
7 than that.
8 So, the want-to-be gangs, a lot of them
9 come up from Minneapolis up to Northern Minnesota.
10 Other tribes, Wind River, had a huge issue with
11 Mexicans marrying Indian women so they could get
12 on the reservation where there is protection
13 there, and set up business.
14 We had issues here of drugs coming over
15 the border from Canada. They basically -- well,
16 they can't now because they extended the ability
17 unless you fly to get from Canada to here until
18 November, but they basically come down, sell their
19 stuff, get caught, get deported, and go back and
20 restock and come back down again. I mean, it's
21 just awful.

1 And one can understand, they've done
2 these adverse effects research, which I think are
3 good, valid numbers. And if you think about a
4 child who is exposed every day -- every day to
5 repeated loss, and I've tried to negotiate with
6 the CDC to add a couple questions, in particular
7 on meth, whenever I was working on a project, and
8 they won't do it. I'm like, you know if you could
9 take the wire BS, whichever school, including the
10 BIE schools, has to administer once every three
11 years, compare that with the BRFSS, I mean, that
12 would be so rich.
13 So, if there is anybody in the audience
14 that needs a project, think about doing that. And
15 nobody's done it. Nobody's done it for other
16 races either, but I think it would be totally
17 revealing.
18 We always believe and we actually
19 developed a position for a wellness promotion
20 specialist in the tribal school, and the whole
21 idea was for this person to augment what the grade
22 schoolteachers were teaching.

1 We funded it with a grant. Whenever the
2 grant money ran out, so did the position. But
3 sadly -- and I'm trained as a physiologist -- I
4 think it's so important. I think we really don't
5 respect our young people enough to tell them
6 things.
7 I once taught gross anatomy to third
8 graders and to first graders because the teacher
9 shamed me into doing it because all the other
10 parents are coming to class. But anyhow, so I
11 tried to figure out, you know, what I could teach.
12 I figure one thing that would last them for the
13 rest of their lives, and my goal was that muscles
14 can only pull. And so, I don't know how many of
15 you had an anatomy class, a little yarn, you know,
16 you put on things, but everybody knows how I made
17 a muscle, and so whenever I walked in a room with
18 a real skeleton, which had some intercostal damage
19 on one side of his ribs, the kids were just like
20 "whoooo" (ph.). And I had them on task for an
21 hour.

1 One of the questions that they asked is
2 how come if I look at my hand and it looks blue,
3 whenever I get cut, I bleed red?
4 Another person wanted to know why the
5 grandmother had to take shots and why she couldn't
6 just take a pill. But the one that I get
7 goosebumps with is one child said what's cancer.
8 So those days we had blackboards. So, I drew out
9 an example for that.
10 A similar scenario with the first graders
11 on task. And if you've ever taught school, to
12 keep little kids on task for that long is nearly
13 impossible. I really think we underestimate.
14 So going back to pre-birth, that's how we
15 -- at least our health system here entertains or
16 what our philosophy is. And the resources that we
17 need to have a significant influence on population
18 well-being are -- and if you get that logic model,
19 it tells them there, too, but availability to have
20 safe housing and nutritious food.
21 Well, we think, you know, people can
22 handle that. You get commodes and to this day I

1 kind of like the block of cheese. But regardless,
2 you can also get a can of lard and other things.
3 So, it's not exactly nutritious. They do offer in
4 the commodes program fresh meat and vegetables
5 now.
6 But then access to cultural traditions.
7 It was back in, I think, '86, a reservation about,
8 oh, almost a hundred miles from here, they were
9 having a spiritual ceremony and they all got
10 arrested. It's like well, don't you know the law,
11 even though it's spiritual and not quote,
12 technically religious, it falls under that
13 category.
14 So, access to cultural activities and
15 traditions is a big deal. I'm really saddened as
16 faculty at the university that whenever I go to an
17 American Indian meeting -- and it's all tribes
18 there from all over the country -- and there's no
19 seats left, I'm kind of like waiting for a young
20 person to get up. It doesn't happen.
21 Also, traditionally for a lot of tribes,
22 you know, you sit down, and a younger person

1 brings you a plate. That don't happen (sic). So,
2 I'm really, really concerned as an elder, oh, my
3 gosh, these youngsters are losing so much of their
4 culture that they don't know some of the basics.
5 Okay, I'm going to have to speed it up
6 here a little bit, I see. And you can read the
7 rest of that, transportation options. You know,
8 up here it's kind of serious when it gets to be
9 minus forty, but the ability to live, work,
10 congregate and so on, and social support.
11 And then historically, American Indians
12 suffer inordinate high infant mortality rates, and
13 no one has determined what the ideology is. It
14 all seems to be different, but it's staggering.
15 And the one thing that, I guess is
16 fortunate about the State of Minnesota, and Ed was
17 part of it, we switched to -- I don't know, it's
18 probably been eight years ago now, but instead of
19 having disparities that we talked about, and we
20 talked about infant mortality disparities, you
21 really get people kind of nervous and nice people

1 get offended or whatever, but we started doing
2 health equity.
3 And an advantage of that is, whenever I
4 go do presentations locally, everybody is like
5 waiting for the disparities talk, you know. So, I
6 point to somebody, and I say hey, how are you able
7 to be here today, and they're like what is going
8 on? And what about you, you know, I'd say.
9 And so, I say what we're going to talk
10 about is resilience, how your ancestors were able
11 to survive to be here today, that's what we're
12 going to work on. So that's what we've been doing
13 in the State of Minnesota for a number of years
14 now. And you had really good presentation going
15 to the residential schools, but to mention that
16 those kids that were taken, literally out of the
17 arms, I mean, can you even fathom that in the
18 United States, and taken to residential schools.
19 The estimates in candor are about four
20 thousand right now. And they just got done with
21 their prime minister elections, so they'll go back
22 to that. And I absolutely guarantee it, it's

1 going to be thousands of people that died,
2 youngsters that died for whatever reason. There
3 was just no communication.
4 As a matter of fact, at the Morris
5 campus, American Indians and World American
6 Indians can attend school tuition-free. And we
7 have in our administrative program the ability to
8 do admission free as well.
9 Loss of community is a huge deal in this
10 country. I've only seen one true community and
11 that's the Portland, Oregon Urban Indians. They
12 work together, everybody has a certain role they
13 have to play. But everybody is doing
14 individualized things now, even tribes. Everybody
15 thinks oh, that's just one group of people. No.
16 They're just like everybody else and all this
17 individualism is happening.
18 Even the First Nations in Canada were
19 able to have a sense of community, and then the
20 internet hit. And the biggest thing is forced to
21 practice learned dependence. And sadly, people in
22 that category, which is a lot of people, don't

1 know, because you give them a lot of satisfaction,
2 a survey test, and they come back and it's like
3 well, you know, a pretty good score. They don't
4 understand because they've been learned dependent
5 their entire life and their parents.
6 So huge issues with the data. I talk a
7 little bit about that, but you should know that
8 over-sampling American Indian populations does not
9 come out accurate. And an example is a State was
10 talking about their BRFSS data, and I looked at
11 the American Indian, I'm like what is -- what
12 number is this? It took me two years, but I
13 finally weaseled it out of the state demographer.
14 And the end for the entire state of American
15 Indians was a hundred and thirty.
16 So, you got to be really careful. And
17 people don't understand that. They think that
18 every Indian is the same and absolutely not.
19 Also surveying by zip codes doesn't work
20 in rural America. And better yet, we've developed
21 data-sharing agreements, and that's helped a lot
22 for people to get involved.

1 ED EHLINGER: Linda, could you wrap it up
2 because we've got another presenter and we're
3 running out of time.
4 LINDA BANE FRIZZELL: Yeah. Okay, so
5 everything is on here and you can quickly do the -
6 - read the red on here, and I just want to get
7 down to trust is a big issue, as mentioned by the
8 previous presenter, all the practices that have
9 been done to Indian people.
10 And this is about violence. Missing and
11 murdered indigenous women had two days of
12 excellent presentation. So, these are all the
13 recommendations. And I highlighted the important
14 parts in red that's easier to read.
15 And other spiritual practices as opposed
16 to religious. A lot of Indians have Western
17 religions, but also there are traditional people
18 who have spiritual practices, and this is my
19 pretty picture and summation.
20 And then that's also a picture and here's
21 my contact information. Sorry to go over.

1 JANELLE PALACIOS: Thank you so much, Dr.
2 Frizzell. You've brought up really important
3 points. You've talked about Indian policy and
4 travel government, which really helps put in the
5 gap, contextualizing everything because you have
6 to have that policy piece to understand why we
7 have health services, why we have a different
8 access.
9 And then you brought up the data piece,
10 which we simply have a really big issue in trying
11 to locate the population, how do we define the
12 population.
13 And I love that you also brought up that
14 Indian Health Service, for all the work that they
15 do, they are five years behind, consistently in
16 the data that they publish. And that is a huge
17 issue.
18 And then you talked about trust. So, we
19 still have a little bit more to go and your
20 presentation actually melded really quickly with
21 Dr. Stemmler's because she will the take on the
22 presentation talking about Indian Health Service

1 as a member that reviewed Indian Health Service
2 facilities.
3 So, thank you. Please stay tuned, Dr.
4 Frizzell, we hope to have a few questions at the
5 end.
6 LINDA BANE FRIZZELL: Okay.
7 JANELLE PALACIOS: Dr. Stemmler, I
8 introduced you a little bit before Dr. Frizzell
9 presented. Do you see your presentation, do you
10 see it loaded?
11 SUSAN STEMMLER: No, I don't see the
12 presentation.
13 JANELLE PALACIOS: Okay. I know we have
14 it.
15 SUSAN STEMMLER: Is it started. I will
16 start screen sharing. Oh, it says that it started
17 screen sharing. Oh, there it is.
18 JANELLE PALACIOS: Okay. Thank you.
19 SUSAN STEMMLER: I want to thank you for
20 inviting me to be able to do this. This is the
21 culmination of six years of work that I've had the

1 opportunity to do with ACOG, the American College
2 of Obstetricians and Gynecologists.
3 And it also is -- kind of ends the time
4 for my career. But you know, before I get
5 started, you know, I would like to give thanks for
6 just being here. My mother is a Choctaw Native.
7 Her name is Thurasue (ph.), but her Choctaw name
8 is Kune (phonetic), and I am Osa Kune. I come
9 from Oklahoma. My ancestors came on the Trail of
10 Tears to Oklahoma, and they settled in
11 Southeastern Oklahoma around Idabel, if you know
12 that particular area, and that's where the Choctaw
13 Nation resides now, and all over everywhere else
14 as well.
15 Okay. So, I have a couple of things that
16 I want to get into. How do I advance? Advance,
17 please. Okay.
18 So, the American College of Nurse-
19 Midwives provides a liaison to ACOG, and I think
20 I'm probably about the third person who has done
21 this. This is the first time, you know, that we
22 have had someone who is of American Indian

1 ancestry to be on the committee though. So, you
2 know, as I'm ending these six years, I am very
3 grateful to be involved in what has gone before
4 me.
5 ACOG has just recently celebrated its
6 50th year anniversary as a contractor with the
7 Indian Health Service for evaluation of women's
8 healthcare, and it covers the -- the evaluations
9 cover all twelve areas of the IHS, but
10 predominantly those areas that provide direct
11 services, labor, and delivery services to Native
12 women. Advance, please.
13 So, in the 2020 census, there were two
14 million -- two point six million Native Americans,
15 and the last national federal registry in, I
16 think, 2019, showed that there were five hundred
17 and seventy=four federally recognized tribes now.
18 Of those federally recognized tribes, there's
19 actually only about a hundred of them that are
20 recognized within the states.
21 This group of people has been a group
22 that has been hidden. They have been invisible,

1 and in particular, the people who are -- who live
2 in urban areas.
3 What I want to address here is how the
4 IHS is working toward making a better life for
5 women and their children by looking at what the
6 morbidity and mortality in pregnancy is, and also
7 for the infant mortality.
8 So, I'm going to take a look at both of
9 those two areas today, and what I will be able to
10 do, because of the agreement that ACOG has with
11 the IHS is, I'm not able to show you any data,
12 however, I have seen data that comes directly from
13 the hospitals. And I have had the opportunity to
14 be able to talk and interview physicians and
15 nurses, nurse midwives, and staff within the
16 majority of the large IHS hospitals.
17 So, it gives me a little bit of
18 background and just being able to tell you how
19 things are. Could you advance, please?
20 So the tribal communities, you know, we
21 look at from Alaska all the way down the Great
22 Plains, all the way to Arizona and New Mexico, and

1 there is -- it's just like a large pathway of
2 wilderness, very few cities, and great poverty,
3 and the issues that are -- that these -- that
4 Native Tribes address in these areas are really
5 more than what I could probably handle myself, but
6 what you are seeing is that they are living in
7 such great poverty that they need to have
8 resources.
9 And while I'm going to be talking about
10 the IHS, IHS system, what I'd like to be able to
11 do is -- you know what, I'm a little flustered. I
12 just need to get over this just a moment. So
13 anyway, I'll get there.
14 Anyway, so what happens is that, you
15 know, these people are living under duress still,
16 you know. You know, we talk about our historical
17 traumas and all of those sorts of things. Those
18 traumas are current, too. And the people who are
19 living there in those -- you know, in the tribal
20 settings, their numbers are decreasing very
21 quickly. The young people are moving to the urban
22 setting.

1 Right now, what we're looking at is
2 somewhere close to, you know, seventy-eight
3 percent of all Native Americans who are living in
4 cities. In Los Angeles alone, we have over
5 seventy-five thousand people who self-identify as
6 Native American in Los Angeles County. It's the
7 largest accumulation of Native American people,
8 and there is one facility in this county that
9 addresses the needs of Native Americans.
10 Now, you know, I was talking about the
11 census. Two-point six million. The last census
12 in 2010, it was one point nine million. I read an
13 article that came out about a month-and-a-half ago
14 from the 2020 census that said oh my gosh, there
15 is an increase of a hundred and sixty percent of
16 Native American people who are identified on the
17 census. This is outstanding.
18 And all at the same time, you know, we
19 think about what's really happening with this.
20 The people who are on their native lands, who have
21 the opportunity to go to an IHS facility for their
22 healthcare, or who are being taken care of within

1 their own tribes and their communities, you know,
2 those people are staying there, but the young
3 people are leaving.
4 When they get to the cities, they don't
5 have any healthcare. They don't have the ability
6 -- they have more resources available to them, but
7 they may not have the money to be able to, or the
8 health insurance to be able to get the care that
9 they need.
10 Now, we had recently, you know, when
11 Obama was in office, we passed the Affordable Care
12 Act. And what that did was, that increased the
13 ability for Native people to be able to get
14 healthcare. And if they were willing, to be able
15 to sign up for healthcare.
16 So essentially, what has happened -- and
17 this is just my suspicion, not necessarily that
18 there are so many more Native Americans because I
19 think that what I was seeing in tribal sites was
20 that they were -- that there was a greater use of
21 long term contraceptives, that younger people were
22 not having the pregnancies that they had had

1 before, that the birth rate, in general, had been
2 decreasing significantly in the tribal hospitals,
3 and they had really, really fallen whereas, you
4 know, some of the sites had a very few deliveries
5 that they were doing but for a number of reasons.
6 Medicaid has been available to mothers
7 and to women, and I think women are taking
8 advantage of that. And I think by joining
9 Affordable Care and being able to identify as
10 Native Americans, they're able to get more
11 healthcare.
12 So, I actually look at the possibility
13 that the Indian Health Service could be in
14 jeopardy in areas where healthcare other than the
15 tribal sites would be available.
16 So, this is something that I suspect is a
17 possibility, but I don't know for sure that it
18 will take, you know, that particular road. But I
19 am concerned about that.
20 Within the tribal communities, the IHS
21 has a love/hate relationship. The tribal
22 communities are tight. They know everybody who

1 lives within their tribal communities and their
2 tribal areas. And like any small town, they have
3 people who are great friends and people who are
4 great enemies and they're rivalries and there are
5 all kinds of things.
6 The facilities on the tribal communities
7 have an ability to employ, and they have been a
8 good source of employment for many of the people
9 who want to remain in the tribal communities.
10 Because of the poverty that's there and distance
11 from cities and, you know, or work, you know,
12 people have to travel a long way for work, or they
13 can work at the hospital, and many of the people
14 do.
15 What happens within the tribal community
16 is they would like to be able to see, you know,
17 their population there use the tribal hospitals
18 because they have investment in them.
19 But I'd like to read something to you.
20 It's not very long. It's a story about Jean Bear,
21 and this was in the Native Times. And anyway,
22 Jean Bear is a young woman and she found out she

1 was pregnant, so I'm just going to paraphrase
2 this. And she did the same thing that women do in
3 Pace, Montana, she drove eighty-two miles across
4 the Fort Belknap Indian Reservation to the nearest
5 hospital that had prenatal care and delivery
6 services for her first checkup.
7 Her route took her past Fort Belknap's
8 Indian Health Service, the facility created to
9 provide healthcare to the reservations and tribal
10 residents, and it's been mandated by treaties in
11 the past to be able for this provision.
12 The problem was is that Fort Belknap IHS
13 had stopped its delivery program, stopped
14 delivering babies in 1970. What we are seeing is
15 that many of the sites have been closing to
16 maternal childcare and no longer continuing with
17 their programs for delivery for obstetrics.
18 So, there are a lot of people who are
19 traveling, just like women in other rural
20 settings, any kind of a rural setting, the
21 distance for them to travel to healthcare is very
22 long. It needs to be planned. They have to have

1 transportation. They need to have somebody who is
2 going to take care of their children. They need
3 to be able to know where they're going, and they
4 have to feel comfortable within the setting that's
5 there.
6 Going back to the ideas within the tribal
7 communities about it being a love and hate
8 relationship, you know, many of the people in the
9 communities complain that somebody else knows
10 their business. You know, it's people in the
11 community that they may not want to have them know
12 what their diagnosis is, and everybody knows. Did
13 you know so and so has such and such happening, or
14 oh, she's pregnant again? She's going to have
15 her, whatever it -- child.
16 Anyway, all of these things are things
17 that are happening within the community and around
18 those IHS facilities.
19 There are tribal councils that support
20 and interact with the IHS facilities in general,
21 generally speaking, there are. And each and every
22 time we would go to one of the IHS facilities, and

1 what would happen within the ACOG group is, we
2 would have a whole slew of facilities that we
3 needed to visit within a certain IHS area.
4 And we would break up into little groups
5 of maybe about three or four, you know, sometimes
6 we would have a group as big as five, but we would
7 go there, and we would have the opportunity to be
8 able to meet the community people. We would get a
9 chance to meet the hospital administration. We
10 would meet all the OB/GYN's, the pediatricians,
11 the neonatologist, whoever they -- you know, the
12 midwifery staff, the nursing staff, everyone who
13 was there within the facility, and it was
14 wonderful to be able to do that, and there was
15 conflict. There was conflict that would happen,
16 you know, between the people within -- what the
17 people, the tribes -- the people within the tribes
18 thought needed to happen and what the providers
19 thought needed to happen. So that was something
20 that was always a bit of a problem for them.
21 Could you please advance the slide?
22 Within the Indian Health System itself, there were

1 issues that would come up. You know, it seemed as
2 though the issues were fundamental. They were
3 things that would -- I think would arise in a
4 place that was isolated.
5 You know, I think about the term,
6 frontier medicine. I never liked that term
7 because it seemed like, you know, it was too much
8 cowboy for me. But it was -- there were
9 situations that would come up where the providers
10 were asked to take care of someone who was a
11 little bit beyond their scope.
12 There were shortages of providers. There
13 were -- you know, one of the big issues, I think,
14 that happened was many of the sites would say, you
15 know, IHS is a centralized organization, and all
16 of the hiring and firing has to come from, you
17 know, their headquarters or from -- you know from
18 the area leaders.
19 And so, they would vet these people to
20 come in, and then they would not get anybody to
21 work. And they would have times where they would
22 have to close down their services because they

1 didn't have providers. They didn't have a
2 physician. They didn't have midwives. They were
3 running short. they couldn't cover every day of
4 the week. There were -- you know, there were
5 different problems that this presented.
6 Many of the sites had to provide housing
7 for providers because so many of the providers
8 that did come, you know, they were doing Locums
9 and they would come and they would stay for three
10 months or six months, and that doesn't give the
11 continuity that is needed there.
12 Another thing was, you know, within the
13 forms that they use. They were using old
14 Veteran's Administration, you know, the charting
15 formats. And they didn't all include -- I mean,
16 they didn't include -- obstetrics was a problem.
17 So, they had hybrid forms of -- for charting. And
18 it made it cumbersome for all of the staff to be
19 able to use the computer and also do, you know,
20 collection of their data on -- in paper form.
21 There are also inconsistent updated
22 medical procedures. You know, this was a problem

1 because if you have people who are coming and
2 going, you don't have somebody who takes
3 responsibility for making sure that your medical
4 procedures are up to date.
5 And so, it means that the people who were
6 there the longest, you know, that job would fall
7 to them, and they may or may not be the person who
8 is appropriate to be able to do this.
9 Inconsistent professional linkages and
10 local healthcare facilities, many of the hospitals
11 -- I have one hospital that keeps coming in mind
12 for me, and that is a hospital that's located
13 right up by the Canadian border, not very far from
14 Glacier National Park, and it has one physician
15 who lives in the area, and that's a good thing,
16 you know, but he's only part-time. He works with
17 the community hospital, you know, the rest of the
18 time, and he only gives the IHS facility a couple
19 of days out of the week. But he's the most
20 consistent.
21 And in fact, the hospital that he works
22 at does not want to receive patients from the IHS

1 facility if they need to be able to make
2 transfers. So, you know, I'm talking about a
3 whole lot of very, very specific problems, you
4 know, that can be -- can be changed within the
5 IHS. And yet, it makes me wonder whether or not
6 it's worth doing those, making those changes,
7 because are the people going to use them?
8 You know, with the young people leaving,
9 you know, leaving the tribes and what is happening
10 is they're leaving the tribal areas, and it leaves
11 fewer people there to be able to serve. Is it
12 worth it to be able to provide physicians and the
13 coverage and all kinds of you know -- to make all
14 kinds of changes to accommodate that type of
15 program?
16 And the other thing, too, is, you know, a
17 lot of the young people are wanting to leave the
18 community and find out about other facilities.
19 Now, I was talking about this woman
20 earlier who had to travel, you know, all that time
21 to go to Billings to be able to go for her
22 prenatal care, and the problem really wound up

1 being that she was doing this, but she was doing
2 it at her choice because she knew that the
3 facility wasn't going to offer her the care that
4 she needed, her IHS facility was not going to be
5 able to offer that.
6 But she wanted to be able to have more
7 care and more options with less time involved.
8 And she drove a total of three hundred and thirty-
9 six miles, you know, to be able to go for her care
10 because she found out she was having twins.
11 Anyway, just -- can I have five minutes,
12 please?
13 The non-uniformity of services within the
14 urban population is really an issue. It sounds as
15 though we have all of these facilities all over
16 the country. There are IHS contracts with thirty-
17 five different states able to support different
18 tribes providing services in the cities, and the
19 problem really winds up being is that the majority
20 of them wind up being for substance abuse and not
21 necessarily for -- not necessarily for prenatal
22 care or for perinatal care.

1 Can you advance, please? So late entry
2 into care or no prenatal care is common among the
3 women that I have seen in the sites. Their
4 perinatal education, I would love to be able to
5 see them learn from each other and have a little
6 bit of group education, but you know, we're not
7 seeing very much of that anymore, and they do have
8 classes, but they're only based on numbers, you
9 know, who they can pull together, who they can
10 bring together to be able to do that.
11 And the issues between women who live in
12 rural areas and urban areas with regard to preterm
13 birth and low birth weight are, you know, they're
14 pretty much consistent across the board, whether
15 it's urban or rural.
16 But the problems that happen on the --
17 among the patients who attend IHS facilities is
18 that they're looking at obesity, diabetes, and
19 substance use. Oftentimes, you know, women are
20 smoking and drinking alcohol throughout their
21 pregnancies. Some are using other drugs, you

1 know, methamphetamine has been a problem, opiates
2 have been a problem.
3 I want to tell you about a woman that I
4 encountered. She had delivered a baby, it was
5 time for her to go home, and she did not have a
6 layette. Because she had not prepared for this
7 birth, I don't know what she thought was going to
8 happen, but she hadn't prepared. The best that
9 they could do was to wrap the baby in newspaper to
10 be able to take -- for her to take her baby home.
11 Community involvement, visiting nurse
12 visits at day one, day three, day seven, and then
13 at two weeks back at the facility are just
14 outrageously important, you know, for these women.
15 You know, we need to see, and we need to know
16 what's happening to the mother, what's happening
17 to the baby.
18 I'd like you to advance, please. Advance
19 the slide. Taking care of the providers. This is
20 one of the biggest problems, is having providers
21 that are consistent, you know, providers who are

1 there, are going to be there longer than two
2 years.
3 The IHS system has for many, many years
4 participated in integration and all kinds of
5 student activities, you know, with students,
6 medical students, and midwifery students, and even
7 nursing students, you know, within their
8 facilities, and the number of people who actually
9 join IHS, or who go to IHS or want to stay in IHS
10 is dwindling.
11 It used to be, you know, when I became a
12 midwife, there were a whole group of Native
13 midwives that were my sisters and supporters and I
14 learned from them and we are still very, very
15 close. But the problem is, is that you know,
16 Native midwives are very, very few and far
17 between. Right now, within ACNM we have sixty-
18 seven across the nation, and I can tell you the
19 names of about 20 who I know very, very well, but
20 where are the others, you know, I just haven't got
21 any clue, because they're not showing up in these
22 sites.

1 You know, there was yesterday, one of the
2 physicians spoke about how people of color tend to
3 go back to their -- you know, to their roots, and
4 it may not be the case, you know, because, you
5 know, for young, let's say nurses, the majority of
6 them are trained in local community colleges.
7 They begin working, and once they start
8 working, what they're doing is they're supporting
9 their families. They're supporting their extended
10 family. They don't have the time or the money to
11 be able to go back to school to continue their
12 bachelorette education, so you wind up with
13 someone who doesn't work within the IHS, but who
14 works in the community hospital and never gets to
15 change her level of employment. I mean, she
16 doesn't get to grow within her profession.
17 Midwifery requires that and you know, I
18 would love to have -- I mean, there were so many
19 nurses that I met who I would love to say okay,
20 you would be absolutely perfect to be a midwife
21 because they've been in those facilities for
22 years, and years, and years, and they have

1 talents, but they have to go back to school, and
2 it's hard to be able to do that. So, we need to
3 look at that as one of the areas that can be
4 improved for Native midwives.
5 So, they're saying one minute. So,
6 telemedicine. My gosh, you would think that we
7 would have telemedicine throughout IHS, and we
8 don't. It would be so great. We have this issue
9 with collaborative care in the IHS systems.
10 You know, I love physicians, I've worked
11 with them for all of my life, but the thing is
12 that midwives actually have the scope of practice
13 where they can do a normal delivery and they can
14 do it on their own license. They don't have to
15 have a physician who is standing over them or one
16 that they report to when they come on shift and go
17 off shift.
18 So collaborative care needs to be
19 identified. Now, ACOG and all of the physicians
20 that I work with there say yes, yes, we want
21 collaborative care. That means, you know, the
22 nurse-midwife can take care of her patients, or

1 she can refer to the physician for, you know,
2 advice, or she can transfer the patient into his
3 service, or she can do whatever -- or they can
4 collaborate on being able to take care of a
5 particular woman together.
6 But the problem really winds up being is
7 the midwife doesn't get to continue her services
8 if the physician isn't available, or isn't on
9 call, or isn't able to respond. So, the clinic,
10 or the, you know, the hospital goes on divert.
11 So, it stops if the physician isn't able to
12 respond. And that's not fair to the community.
13 It's not fair to the facility. It's not fair to
14 the midwife.
15 So anyway, moving on. So, the other
16 thing that I think is really important is this
17 idea of contingency planning for early delivery.
18 I particularly like the system that they use in
19 Alaska. In Alaska what has happened is all of the
20 tribes have come together and they have pooled
21 their money, and they make in Anchorage like the
22 Center of Excellence. They have developed a

1 system. It's like a regional perinatal system
2 that is there that seems to be working.
3 The problem winds up being in Alaska is a
4 big, big place. So, if you have a small town, a
5 small fishing village above the Arctic, you have
6 to transport someone in. And you need to have at
7 least a minimum of seven hours to be able to
8 transport that person from, you know, from the
9 care that they're receiving at the -- you know,
10 the facility, the rural facility to take them into
11 Anchorage.
12 But the same thing happens if you're
13 talking about Montana. If there's a twenty-foot
14 snowdrift, you know, nobody's going to make it for
15 those three hundred miles or whatever that it
16 takes to be able to get to the next hospital. So,
17 it's -- and they can't use helicopters, they need
18 to use fix swing and there isn't a place to be
19 able to go, there's no place to land.
20 So, I think, you know, we need to be able
21 to develop ways of being able to help women and

1 support women in being able to get the care that
2 they need.
3 Can you advance? Am I done? Yay. Okay.
4 So, I'm open for any questions.
5 JANELLE PALACIOS: Thank you so much,
6 Dr. Stemmler. We actually are at a time at this
7 moment, and I've been asked to for any questions
8 to put them in the chat box. I want everyone to
9 know that Dr. Stemmler and Dr. Frizzell joined us,
10 and they have a lot of experience, and it was a
11 bit of a fandangle to secure this segment because
12 this is a very popular time in our nation right
13 now for lots of amazing conferences are happening,
14 and both Dr. Frizzell and Dr. Stemmler took time
15 from their lives to be a part with us, to share
16 their expertise.
17 So, I thank you very much, like hands for
18 Dr. Frizzell and Dr. Stemmler, and I know we have
19 lots of questions. But if I could do like a
20 thirty-second kind of review. And these are some
21 things that I heard between the two presentations.

1 Indian Health Service is underfunded.
2 There are data issues that we have in identifying
3 and locating the population.
4 IHS publishing data is about five years
5 old. IHS OB services are pretty much like serving
6 the maternity desserts in rural healthcare,
7 especially, that a number of IHS OB facilities
8 have closed down over the years, leaving some
9 women having to travel hundreds of miles to secure
10 care.
11 IHS system relies in part on Locums,
12 which may not have a big investment in the
13 community, and so there is this lack of community
14 continuity that Dr. Stemmler shared with us.
15 Of recently, to date, the IHS has used
16 paper charting, and I believe they're moving
17 towards, or they have maybe all moved now towards
18 electronic charting but that there were still
19 remnants when Dr. Stemmler was reviewing IHS
20 service facilities of old VA charting that had to
21 be hybrid for data collection for OB information.

1 Again, this consistent lack of
2 opportunities for IHS to link with the community
3 was one theme. Women -- IHS urban sites or funded
4 sites predominantly specialize in substance use.
5 And so, there's little other -- there's other work
6 that's happening in urban areas, but a lot of the
7 main focus is on substance use. So, there is a
8 lot of opportunities to focus on maternal infant
9 health.
10 Dr. Stemmler also shared that home
11 visitation programs would greatly improve access
12 and education and probably help outcomes from her
13 expertise, and there is this IHS workforce issue.
14 I understand the private conversation with Dr.
15 Stemmler that to become a physician or a midwife
16 to go through that process to be vetted, to become
17 an IHS provider, it can take quite a long time.
18 And while you're waiting for that, sometimes
19 physicians or providers are actually hired out to
20 other facilities and they don't accept IHS to
21 become an IHS provider, and that there is a

1 dwindling lack of indigenous representation in the
2 providers.
3 Maximizing telemedicine is definitely an
4 area for advancing collaboration, but there needs
5 to be this link that allows patients to be still
6 cared for by midwives. And so, telemedicine and
7 collaboration are absolutely necessary and there
8 needs to be really strong methods for this.
9 And then lastly, Dr. Stemmler shared a
10 little bit about the obstacles that rural, very
11 rural areas like Alaska has that contingency
12 planning and looking for opportunities for tribes
13 and communities to try to kind of identify the
14 problem and come up with their solutions. And
15 that's what I heard from Dr. Stemmler's
16 presentation.
17 Ed, I will defer to you, but I know for
18 sure, please put your comment box. I have a few
19 already, but I will be adding to them. This is
20 not -- we're not done with this conversation in
21 general.

1 ED EHLINGER: Yeah, that's the point.
2 There were lots of questions that were raised,
3 lots of issues that were raised. This is just
4 scratching the surface. This is the beginning of
5 the conversation.
6 So put them in the chat and my hope is
7 that I can meet, and Janelle will meet with the
8 health equity workgroup, and we can really think
9 through all of these questions and all of these
10 issues as we plan for another session in December
11 in follow-up of this one.
12 So, with that, we're going to take a
13 break until twenty-five to the hour. So, we've
14 got about eight minutes, and then we'll come back
15 at twenty-five to three, and then we will have
16 public comment right at three o'clock. We'll stay
17 on schedule for that.
18 So, enjoy these next eight minutes.
19 (Whereupon, a recess was taken.)
20
21 **BREAK**
22

1 **FINANCING OF CARE FOR PREGNANT AND POSTPARTUM**
2 **INDIVIDUALS**

3 ED EHLINGER: Thank you for accommodating
4 a little bit shorter time. Like everything else,
5 we’ve got lots to cover and there’s just never
6 enough time and a lot of good information. But
7 this is an ongoing process that we will continue.
8 And just like we did with the indigenous
9 health at our meeting in June, we identified the
10 fact that financing of maternity care, perinatal
11 care needed a lot more discussion. So, Steve
12 Calvin has agreed to sort of tee us up on that
13 issue. And so, we’ve got about twenty-five
14 minutes for Steve to kind of walkthrough with some
15 of the issues related to financing of care.
16 So, Steve, you’re on. So, unmute
17 yourself and take it away.
18 STEVEN CALVIN: All right. So, I have a
19 short, I think twelve slides here. I think I’ll
20 call this the cliff notes version. I think it’s a
21 good way for us to just kind of get started. It’s
22 a broad overview.

1 But I don't think that we can get very
2 far in proposing changes, understanding things. I
3 think that the two presentations just previous to
4 this about the Indian Health Service and the
5 desires of Native peoples to be cared for by folks
6 that really are paying attention to their needs.
7 There's all the financing, both Indian Health
8 Service and Medicaid and all of those things all
9 tied together.
10 But this is a broad overview of all
11 public, private, and other payments for care that
12 are provided to American mothers and babies. Next
13 slide, please. There we go. Okay.
14 So, a disclosure, I'm -- oops, let's go
15 back. So, a disclosure, I'm a maternal fetal
16 medicine specialist who had a twenty-five-year
17 career of taking care of the most complicated of
18 pregnancies, so I know all the bad things that can
19 happen. But subsequently, I started working with
20 midwives and trying to integrate a midwife-led
21 model into the larger system.

1 So, I'm the -- I've put kind of my money
2 and everything where my mouth was by beginning and
3 working with midwife colleagues at the Minnesota
4 Birth Center where we have two accredited
5 freestanding birth centers that work very well,
6 clinically with collaborating hospitals, and we've
7 also developed the birth bundle, and it's an
8 episode payment model.
9 So that's my disclosure. I have skin in
10 the game and my skin is in the game because I
11 believe -- I believe that the system needs to
12 change. Next slide, please.
13 So here is the problem. We all are aware
14 of the great successes of a lot of the technology
15 that we've developed in the care of pregnant women
16 and newborn babies, but despite being the world
17 leader in that development, we spend more than any
18 other country for maternal neonatal outcomes that
19 consistently lag those of other developed nations,
20 and it's very well documented.
21 Probably the bigger problem -- that's a
22 big enough problem. The bigger problem is that

1 our system currently -- or continues to
2 demonstrate disparities. They're based on race
3 and geography. And we've heard about that in all
4 of our meetings. Next slide, please.
5 So, this is just to get a sense. Like I
6 said, this is the cliff notes version. I do want
7 to leave time for questions and comments, but to
8 make sure we get done by three, the -- so if you
9 go on the top line, the total amount of spending
10 for pregnancy care. So, this comes from the
11 National Vital Statistics reports.
12 In March of this year, forty-two percent
13 of the payment for pregnancy care is Medicaid. A
14 little over 50 percent is private insurance, and
15 then self-pay and others.
16 So self-pay actually turns out to be
17 three or four percent and the other includes
18 CHAMPUS and military programs, as well as the
19 Indian Health Service.
20 And then if you go down to the next level
21 here, twenty-nine percent of Medicaid, white
22 mothers, make up a little over 29 percent of

1 Medicaid payments. Almost sixty-four percent of
2 private insurance payments, and then also the out-
3 of-pocket and self-pay.
4 Of note is that mothers who are from the
5 black community make up almost two-thirds of the
6 coverage for Medicaid and private insurances are
7 twenty-nine percent.
8 And then the Hispanic population as well
9 is higher than the white population. And the
10 takeaway that I got from this is that since
11 Medicaid covers two-thirds of the births to black
12 mothers and, you know, about three out of five
13 births for Hispanic mothers, Medicaid reform
14 really is crucial to addressing outcome
15 disparities based on geography and, for sure,
16 race.
17 So, this, to me, I've just tried to kind
18 of dig deep into it and find out, you know, where
19 is the money flowing, and where is it going and
20 where is it coming from. Next slide, please.
21 This is a very interesting study that
22 came out in March of 2020 from the University of

1 Washington. It's U.S. spending by payer and
2 condition over the 20-year period from '96 to
3 2016. It's a very, very helpful -- it's a very
4 helpful summary. I would commend this study to
5 you.
6 What it showed was a hundred and forty-
7 three billion dollars were spent in 2016 on eight
8 pregnancy-related conditions that are among the
9 one hundred most expensive conditions analyzed.
10 You might wonder what is the most expensive
11 condition, and it actually turns out to be neck
12 and back pain in the United States.
13 Number twelve was the pregnancy and
14 postpartum care, which was a large portion of the
15 -- of that hundred and forty-three billion.
16 Preterm birth complications came in at
17 twenty-eight billion dollars. Well infant care,
18 seven billion, indirect maternal complications,
19 hypertensive disorders of pregnancy, other
20 maternal disorders, and then some of the really,
21 you know, difficult situations of neonatal,
22 encephalopathy, and other neonatal disorders. But

1 it all adds up to a hundred and forty-three
2 billion dollars. It's a lot of money that is
3 spent for these conditions that are related to
4 maternity and newborn care. So next slide,
5 please.
6 So, a couple of insights came to me about
7 that, is that you know, forty-two percent of all
8 U.S. births are paid for by Medicaid, but
9 actually, seventy percent of the total spending
10 for pregnancy and newborn care is made by private
11 insurance and out of pocket payments.
12 I had a conversation with an acquaintance
13 of mine, who is a retired CEO of a major company,
14 and it was a big shock to him. I mean, it has
15 implications economically that there is
16 significant private subsidization of the public
17 program pregnancy care. So, it's important, I
18 think, that we know that the public funds expended
19 are adequately serving those who are supposed to
20 be served, and that, I think, should be a focus as
21 we continue to look at these, as we continue to
22 look at this issue. Next slide, please.

1 So, the pregnancy care pie, this Truven
2 study has been referenced a lot and it's fairly
3 old. I mean, it's almost -- you know, it's eight
4 years old. But it showed that two-thirds of the
5 amount spent on pregnancy, and likely newborn care
6 as well, actually goes to facility fees. The
7 other portion there on the left is actually
8 professional fees, and then the rest is imaging,
9 studies and labs, and pharmacy. Next slide,
10 please.
11 And these are the numbers that at least
12 the Truven study, which looked at both private and
13 commercial insurance, and Medicaid payments in a
14 number of states. This was not a general national
15 thing.
16 But this is from, you know, eight years
17 ago, and it shows these are the total amounts for
18 maternity and newborn care, both commercial and
19 Medicaid. So significant amounts of money are
20 being spent. Next slide, please.
21 So, here's what I would just describe as
22 the Medicaid maternity money flow, just getting

1 the context in. Most people, I don't think, have
2 been able to kind of sort this out, but to just,
3 you know, get the context that Medicaid operates
4 under federal guidelines that began with the birth
5 of Medicaid and Medicare in 1965, and that federal
6 payments, in general, have been providing about
7 fifty percent of Medicaid funding. It certainly
8 varies based on a variety of situations and time
9 frames.
10 At the state level, the Medicaid program,
11 and other programs like it are the major expense
12 in most states. And there are because the
13 Medicaid program is governed at the state level
14 and the national level, that there are about fifty
15 plus, because if you include territories and
16 whatnot, variations in Medicaid eligibility and
17 implementation. So, it's all over the map.
18 The eligibility ranges from what I could
19 determine for a family for a pregnant woman for
20 newborns from a hundred and thirty-eight percent
21 to up to three hundred and twenty-six percent of
22 the federal poverty level. So, I think that there

1 is definitely a -- a good thing to say is that we
2 tend to value this kind of care. Eligibility, I
3 know for my state of Minnesota, it's virtually
4 impossible not to be eligible for care.
5 There has been an accelerating transition
6 from direct fee for service payments over the last
7 twenty years to contracting with managed care
8 organizations, so Medicaid MCOs
9 And then going to the right side of this
10 slide here, the Medicaid MCOs currently provide
11 sixty-nine percent of the Medicaid care
12 nationally. That number has been growing. Six
13 large firms have almost fifty percent of the
14 Medicaid managed care market.
15 All of the states make general capitated
16 monthly payments to managed care organizations
17 when they're utilizing managed care. And it's, I
18 think, thirty-seven states or forty, that number
19 has increased.
20 And some states, like my state of
21 Minnesota, make monthly payments to the managed
22 care organizations for the specific care of

1 mothers and newborns until they're one year of
2 age. Next slide, please.
3 The Medicaid and CHIP Payment and Access
4 Commission is a very useful source of information,
5 and in September, just earlier this month, they
6 released a report called Value-Based Payment for
7 Maternity Care in Medicaid Findings from Five
8 States. And they just did kind of a summary.
9 There are some states that are paying for
10 episodes of care, pay for performance, and
11 pregnancy medical homes. They had a -- they
12 commissioned a study looking at states of
13 Arkansas, Connecticut, Colorado, and North
14 Carolina, and Tennessee, and they looked at these
15 various value-based payment models. And my
16 takeaway from this issue brief, which is very
17 helpful is, if we look just at the episodes of
18 care, which is one of the value-based methods,
19 they were largely focused -- and this is their
20 conclusion -- on cost reduction with few quality
21 measures.

1 It was really uniformly a retrospective
2 payment with the attribution of the pregnant woman
3 or the baby to the delivering provider. Which as
4 most of us know, the delivering provider may have
5 had very little to do with the prenatal care and
6 the other aspects of care.
7 And it was mostly a focus on professional
8 services without much focus on the major expense
9 of facilities. When we look at pay-for-
10 performance value-based models, it's mostly
11 incentives to meet limited quality measures, but
12 not on the cost of the care. And cesarean section
13 rates are included in those pay for performance
14 measures, but the major focus, it seems to me, and
15 I think it was articulated in this issue brief,
16 the major focus is on completion of risk and
17 health screenings. So, if you did the health
18 screening and could document it, there was an
19 extra payment.
20 Medical homes, I think, are certainly
21 important because they are focusing on addressing
22 clinical, behavioral, and social determinants of

1 health as well. The payments, though, for those
2 value-based models were just payments for being
3 part of the medical home and it was appropriate
4 support for patient engagement, community
5 supports, and then population health. Next slide,
6 please.
7 So, this is just my perspective. The
8 solution that high-value perinatal care, these are
9 the things that are required. Transparency is
10 really important. And there is a very spotty
11 amount of transparency throughout the country so
12 that detailed reporting of public program,
13 pregnancy, and newborn care payment information is
14 very, very hard to come by.
15 Accountability is really going to be
16 important so that regular detailed reporting of
17 the outcomes. And then also patient satisfaction
18 scores, which we are all recognizing is incredibly
19 important. You can have good outcomes, but if
20 you're making people miserable in the process,
21 that's not a good thing.

1 And then requiring financial and outcome
2 data. When managed care organizations are bidding
3 and providers are bidding for contracts, and
4 thinking about innovation, implementing clinical
5 models that are really proven. The Centers for
6 Medicare and Medicaid Innovation and Strong Start,
7 we've talked about it a lot, that is a model of
8 care that is proven to demonstrate really good
9 outcomes, and we certainly have to focus on
10 culturally competent patient-focused care by teams
11 and facilities that are paid for value and not for
12 how much they do.
13 Eventually, I foresee that transition to
14 some kinds of prospective comprehensive episode
15 payments are one way to get better collaboration
16 among teams and to get better value for the care.
17 And I'm almost done and then we can have some
18 comments and questions because I know there are a
19 variety of them. Next slide, please.
20 So, I've heard things referred to as a
21 confusopoly (ph.). So, Scott Adams, the creator
22 of the Dilbert cartoon, he has a great quotation

1 that the healthcare topic is confusing because
2 that's how you keep margins high.
3 If Congress or the public ever started to
4 understand healthcare, we would know which buttons
5 to push to lower the profit margins in the
6 industry, but by keeping things complicated, no
7 one can explain to anyone else what needs to be
8 done for the public good.
9 And with that, I'm done, Ed, and I think
10 we can -- do you want to go from the chat and have
11 the questions or what, what would you like to do?
12 EDWARD EHLINGER: Yeah, raise your hand,
13 we do have some time for questions. So, Steve,
14 this is really helpful, it starts to frame it. My
15 question is, did MACPAC come up with some
16 recommendations that we could look at, or are
17 there things that SACIM could do based on those
18 data to actually come up with some recommendations
19 relative to perinatal care?
20 STEVEN CALVIN: Yeah, I don't think --
21 they don't really have any specific
22 recommendations. They even note that some of the

1 states have completed their testing of some models
2 and then just, the program is over with.
3 So, I think that it does give us an
4 opportunity to maybe come up with some
5 recommendations.
6 EDWARD EHLINGER: Are there questions that
7 people might have?
8 Explain a little bit more to me than the
9 total amount of care provided by private insurance
10 and Medicaid, you know, the seventy percent, the
11 forty percent, explain a little bit -- I was a
12 little bit confused what that actually meant.
13 STEVEN CALVIN: Oh sure. Well, it's
14 actually so forty-two percent of pregnancies are
15 paid for by Medicaid. Seventy percent of the
16 total spending on pregnancy care in the U.S. is by
17 private -- by non-governmental entities.
18 That was a little bit confusing. I tried
19 to explain it better, but I'm sorry about that.
20 It's just that -- and you know, you hear about it
21 when you hear discussions within healthcare
22 organizations when they start talking about the

1 euphemism of payment -- of you know, kind of payer
2 mix, you know, they're hoping to have the higher
3 paying commercial payments or patients -- and not
4 that they don't want to take care of patients that
5 are on public programs, but the public programs
6 pay significantly less.
7 EDWARD EHLINGER: Dr. Barfield.
8 WANDA BARFIELD: First of all, I want to
9 thank you, Steve, for a nice, concise summary of a
10 fairly complicated subject. And I did wonder,
11 also, in addition to some of the points that you
12 raised around delivery, some of them also relative
13 disincentives, which then leads and ties to the
14 talks that we heard from our colleagues in the
15 earlier segment about how women can't get access
16 to care because the cost is around the delivery
17 event.
18 And also, the other thing is with regard
19 to high-risk infants, often the care is limited to
20 a certain time period by which providers then tend
21 to maybe shift babies away.

1 STEVEN CALVIN: Yeah, no that's true, and
2 it turns out -- I mean, if you really start
3 digging deep, the neonatal piece of this is the
4 most complicated, and I'm not an expert on it, but
5 the Dartmouth Institute has done really good work
6 about how many neonatal beds there are, how many
7 neonatologists there are, how they're distributed
8 around the country, kind of the level of care and
9 the level of acuity of care. The largest spending
10 of neonatal services is actually that, you know,
11 late preterm where babies end up in ICUs that
12 there might be other options.
13 WANDA BARFIELD: But how do we change the
14 dialogue in the discussion from one of say, for
15 example, bundled payment to one that makes more
16 sense for pregnant women and infants, what would
17 be your thoughts about that?
18 STEVEN CALVIN: Well, I think it's
19 important to have teams really working together,
20 and the only reason that I have an affinity toward
21 the bundled payment is because that's -- if you
22 look at how things happen with orthopedic surgery,

1 you know, you see that there is a specific thing
2 that's done and if you have the pre-op, post-op,
3 all that working together, you can actually get
4 better outcomes for lower costs.
5 So, I'm not -- you know, I'm not such a
6 huge fan of having the bundled payment, but that's
7 one way of -- you know, I am a fan of it, but I
8 don't think that's the only way. I just think you
9 have to have teams working together. And
10 certainly, there are hospitals in major
11 metropolitan areas that do a tremendous job, you
12 know, I know in D.C. and here in Minneapolis and
13 St. Paul.
14 So you have to incentivize people to work
15 together so that you don't have anesthesiologists
16 worried about when am I going to get paid for my
17 epidural, and perinatologists want to get paid for
18 the ultrasounds they do, a package of care, at
19 least a requirement of a package of care,
20 depending on how you -- you know, you don't have
21 to pay for it as a single bundle or pieces of a
22 bundle, but it has to become more comprehensive

1 because that -- that's just been leading to the
2 chaos.
3 EDWARD EHLINGER: Belinda.
4 BELINDA PETTIFORD: Steve, thank you, that
5 was an excellent presentation. Question. In the
6 Medicaid numbers you were looking at, would this
7 include like if a state is paying an enhanced
8 reimbursement for like centering pregnancy or if
9 they're paying for bill of services, does this
10 cover all of Medicaid, or is it just covering the
11 clinical component?
12 STEVEN CALVIN: No, I think it's all of
13 it, Belinda. And it's important to point that
14 out. It's the doula services, centering
15 pregnancy. Those were all of the pay for
16 performance things. Or medical homes, too.
17 And there is certainly appropriate focus
18 now on doula services, which I think it's really
19 crucial that we address that and support that.
20 EDWARD EHLINGER: Steve, you mentioned at
21 the beginning, you know, the work being in Indian
22 country with Medicaid and the fact that you've

1 worked with the Indian Health Service, I believe,
2 or on reservations in the past. Do you see -- and
3 from your experience now, looking at these data,
4 is there some way that we can link these and
5 leverage these things and actually enhance care
6 for everybody and financing for everybody,
7 particularly for the American Indian population?
8 STEVEN CALVIN: Yeah, I think one of the
9 things might almost be like a voucher program. I
10 know the two previous presentations describing how
11 some mothers didn't really -- not to denigrate the
12 Indian Health Service. There are a lot of
13 complicated reasons and great care is provided
14 there too, but to just allow folks to choose what
15 care best serves them.
16 I don't know if Susan or others would
17 agree with that, but to me, that sounds like the
18 kind of thing that might be helpful.
19 EDWARD EHLINGER: Good. Susan, do you
20 want to respond?
21 SUSAN STEMMLER: I do. I think what has
22 happened with, you know, in recent years, the

1 majority of the people who are covered by
2 Affordable Care health programs have the option to
3 be able to choose. And you know, they're more in
4 the city, but they can also choose to be able to
5 go to IHS facilities as well. IHS is able to bill
6 for Medicaid and for Medicare. So, you know, they
7 have the opportunity to choose.
8 I don't know if I made the point clear.
9 When they were talking about the 2020 census and
10 having almost a doubling of the Native American
11 population, what it says to me is that people are
12 self-identifying, and they are self-identifying
13 around the idea that they are able to get
14 healthcare other than the IHS.
15 And because there are seven hundred and
16 fifty-four tribes that are out there, and to be
17 able to get into IHS care, you have to be able to
18 document your Indian -- you know, blood, your
19 lineage, they're not able to get care within IHS.
20 So, this is a better, you know, opportunity for
21 people to get the healthcare that they would need.
22 EDWARD EHLINGER: All right, we --

1 LINDA BANE FRIZZELL: May I respond to
2 that as well?
3 EDWARD EHLINGER: Sure.
4 LINDA BANE FRIZZELL: People need to
5 understand it's kind of a whole different
6 category. And the Indian Health Service has used
7 managed care, for lack of a better term, since
8 1955, where it's actually rationed care.
9 Now a few years ago they changed the
10 ability for contract health, which amount to well,
11 if that cataract, good look getting any services.
12 Now, if you need a heart transplant and they're
13 going to get ahead of you.
14 So basically, folks believe, well, if you
15 aren't bleeding, you know, you aren't going to get
16 the services. So, they may have to wait for a
17 couple rounds of federal funding to do that. But
18 in the same, since that federal funding is a
19 hundred percent of Medicare -- or excuse me,
20 Medicaid patients.
21 And there is a system that was
22 established in, I think, 2017. I got grilled when

1 I testified the fact it should be paid for
2 services through, which means referral to like
3 care hospitals and things like that.
4 Now all the tribes have to do is develop
5 policy for the referral. The patient can go
6 wherever they want, and then the tribe bills and
7 then reimburses the facility. So, it's a big
8 change. It's a different pot of money from the
9 discretionary funds, and some folks, elected
10 folks, have tried to mean test us on our
11 reimbursement from outside providers, but we held
12 them off with the Indian Health Care Improvement
13 Act.
14 So, I don't know if that confuses or
15 explains anything.
16
17 **PUBLIC COMMENT**
18 EDWARD EHLINGER: Thank you, Linda. We
19 are at the top of the hour, and I really would
20 like the fact to stay consistent and respect the
21 time for any public comments that we have. So, I
22 think we can come back to this conversation when
23 we talk about sort of next steps because I think

1 it really leads into a lot of what are we going to
2 do from here.
3 And so, Steve, thank you for that and I
4 hope people can stick around for that conversation
5 and we can bring it up as part of the next step.
6 So, Vanessa, public comment.
7 VANESSA LEE: Hello everyone, we are
8 moving into public comment. To the committee
9 members, we did receive two written comments. You
10 should have seen them in your briefing book. One
11 comment was in the original briefing book, and
12 then the second written comment came and hopefully
13 got to you yesterday evening with some other
14 supplemental materials for your briefing book.
15 We do have one request for an oral public
16 Comment from Dr. Barbara Ostfeld. And while Emma
17 unmutes her, I'm just going to introduce her. She
18 is a professor in the Department of Pediatrics at
19 Rutgers University, Robert Wood Johnson Medical
20 School, and she's also the program director at the
21 SIDS Center of New Jersey.

1 Barbara, do you want to test your mic.
2 I'm hoping they've been able to unmute you.
3 BARBARA OSTFELD: Yes. Can you hear me?
4 VANESSA LEE: Yes, perfect, thank you.
5 Welcome.
6 BARBARA OSTFELD: Thank you. Thank you
7 for the opportunity to offer these comments. I
8 want to add to your introduction that I'm also a
9 grandmother of seven blessings and I probably
10 learn more from that than all my many years in the
11 field.
12 I will address Sudden Unexpected Infant
13 Death, SUID, and the potential impact the pandemic
14 may have in increasing SUID rates and diminishing
15 health equity across population groups.
16 I recommend that the impact of Covid-19
17 be measured not only in terms of the morbidity and
18 the mortality of the disease itself. And also, in
19 terms of adverse outcomes associated with its
20 potential impact and the family.
21 In particular, I wanted to address
22 situations in infant care practices that have been

1 associated with a higher risk for SUID as these
2 circumstances and behaviors may have increased in
3 the pandemic.
4 Emerging regional and global studies
5 document a rise in risk elevating conditions and
6 underscoring to explore a potentially indirect
7 impact of Covid-19 on infant mortality.
8 Moreover, in that Covid-19 cases,
9 hospitalizations and deaths are disproportionately
10 greater in communities with larger black and
11 indigenous populations as two examples. There's
12 also concern that already existing health
13 inequities in SUID will further increase.
14 Especially concerning is evidence that
15 racial disparities, for example in Covid-19 are
16 also seen in those under twenty-five years of age,
17 potentially individuals with young infants.
18 When the SIDS Center of New Jersey was
19 first established in 1987 with a grant from the
20 New Jersey Department of Health, not much was
21 known about reducing the risk. The work was
22 mostly around supporting parents and their grief

1 that over the years our research and that of so
2 many others has led to recognizing that even
3 though many sudden unexpected infant deaths remain
4 of unknown cause, we do know the circumstances
5 that elevate risk, and we do know how to reduce
6 those risks.
7 These are codified in the safe infant
8 sleep guidelines of the American Academy of
9 Pediatrics and SUID rates dropped as these
10 practices were adopted. But even before a newborn
11 is ever placed to sleep, some are already more
12 vulnerable to SUID. The adverse antecedent
13 determinants are well known.
14 A sampling includes preterm birth, smoke
15 exposure, diminished access to care, maternal
16 stress, maternal depression, and maternal pre-
17 conceptional health challenges and poverty.
18 Population group disparities in these determinants
19 contribute to disparities in SUID. And health
20 inequities are also driven by the impact that
21 implicit bias or overt discrimination has on

1 confidence and trust in accessing services even of
2 those not living in poverty.
3 Already data from the pandemic year
4 indicate a rise in preterm birth among women
5 diagnosed with Covid-19, more interesting home
6 birth, changes in smoking habits, a decrease in
7 breastfeeding, arising depression, disruptions in
8 prenatal care because of stretched healthcare
9 resources or fear, and challenges to economic
10 stability.
11 And safe infant sleep practices, which
12 also exhibit population group disparities may be
13 compromised in the pandemic as well. If the
14 illness of the home requires that an infant be
15 cared for elsewhere, are the alternative
16 caregivers, such as grandparents, being advised
17 about current recommendations for safe infant
18 sleep? Do they have a crib that meets current
19 safety standards? Will visits to new and
20 exhausted parents from helpful relatives be
21 curtailed? And how will a resulting increase in

1 parental fatigue compromise safe infant sleep
2 practices?
3 Mother nature is an unethical researcher,
4 and her interventions are harsh. But always in
5 these disasters, much is revealed about
6 vulnerability and new measures of safety can
7 emerge.
8 We, as researchers, providers and
9 policymakers have an opportunity to make that
10 happen. Finalized data and SUID rates from '20
11 and '21 is not yet available. But should there be
12 a change in SUID rates, age of death, or
13 population group disparities and rates, for
14 example, we need to understand why and build from
15 there. And that's what I wanted to bring before
16 the group. So, thank you for this opportunity.
17 EDWARD EHLINGER: Thank you.
18 VANESSA LEE: Thank you so much, Dr.
19 Ostfeld. I see some comments coming in. We
20 don't, as I mentioned, have any other requests for
21 oral comments, but I wanted to ask if any -- if
22 either of the written commenters were on the line

1 and did want to say anything orally. We received
2 one from the Kansas Breastfeeding Coalition and
3 the Inter-Tribal Council of Arizona.
4 So, if you are on the line and would like
5 to speak, we do have some time for that. You can
6 just raise your hand and our logistics contractor,
7 Emma, will unmute you.
8 EDWARD EHLINGER: While we're waiting for
9 that, does anybody have a comment or question for
10 Dr. Ostfeld?
11 UNIDENTIFIED SPEAKER: All right, Vanessa,
12 I rewrote the questions I will read from the
13 Inter-Tribal Council right after the presentation
14 from the indigenous panel.
15 VANESSA LEE: Great. Thank you.
16 UNIDENTIFIED SPEAKER: I have it on record
17 there, but we originally planned to have Suzanne
18 England from Indian Health Service to give a
19 presentation, but she was not able to join us.
20 So, this is definitely a conversation that will
21 happen in the future, and we'll be able to have
22 more answers to some of these questions coming up.

1 EDWARD EHLINGER: Dr. Peck.
2 MAGDA PECK: I want to thank you for your
3 comments in the public comment period, Dr.
4 Ostfeld. And I want to revert what the national
5 center for fetal and infant mortality review has
6 posted. And it's a lovely segue into the five
7 minutes more we're going to have to follow up from
8 yesterday's conversation about the power of
9 sentinel event review methodology and not waiting
10 for the rates rations to proportions to come in,
11 but in real-time monitor through case review what
12 is happening.
13 And knowing that SUID deaths are both
14 monitored in child death review and the fetal
15 infant mortality review processes, I'm glad to see
16 that this is -- there's heightened awareness about
17 the vulnerabilities further revealed and
18 exacerbated by Covid-19.
19 So, I'll bring your question into our
20 comments that we'll have following this, and it's
21 a wonderful way for us to raise even heightened

1 awareness of this time of opportunity and
2 vulnerability.
3 EDWARD EHLINGER: Vanessa, anybody else
4 stating that they want to have any public comment?
5 VANESSA LEE: I'm sorry, I don't see any
6 other hands raised at this time.
7 EDWARD EHLINGER: Okay. Then we shall
8 proceed on.
9 VANESSA LEE: Thank you, again, Dr.
10 Ostfeld. Thank you, Ed, and to the committee.
11

12 **QUESTIONS AND ANSWERS FOR DATA TO ACTION:**
13 **STRENGTHENING MCH-RELATED SENTINEL EVENT REVIEW**
14 **APPROACHES, SYSTEMS AND USES: MATERNAL (MMRC,**
15 **FETAL/INFANT (FIMRI), AND CHILD (CFR) FATALITY**
16 **REVIEW**

17 EDWARD EHLINGER: All right. And we said
18 yesterday that we would spend a little bit of
19 time, any questions related to the sentinel event
20 reviews and the session that Dr. Peck moderated.
21 And Magda, were there some questions that came up
22 that you wanted to raise at this point in time?
23 MAGDA PECK: I do. And I am hoping that
24 we are joined, again, by Dr. Sara Kinsman and
25 Julie Zaharatos. So, if they are on, if they

1 would just -- Vanessa, you can maybe confirm that
2 they have been able to join us. We told them 3:15
3 and we're actually three minutes ahead, so I will,
4 in anticipation of that just, say thirty seconds
5 of recap for those who were not with us yesterday
6 or there's been much in between.
7 We did hear presentations about an update
8 from the 2019 briefings specific to the maternal
9 mortality review process where the coverage had
10 gone from limited to almost extensive across the
11 nation. So, we've seen also an expansion in fetal
12 and infant mortality review and child death
13 review. We've seen a maturation of these data
14 systems in terms of dashboards have ability to
15 present aggregate data and what is learned.
16 We heard about the increase of
17 utilization of family interviews, which is
18 essential to be able to bring the story of the
19 lived experience and qualitative data forward and
20 that is becoming more of a practice within the
21 maternal mortality review processes and further
22 and fetal infant mortality review as well.

1 And we heard some examples of how these
2 data are being used to impact both awareness and
3 policy and programs at state and local levels.
4 So, we had a lot of information from our
5 colleagues yesterday.
6 The first question that was raised to us,
7 and I was wondering, can you pin me in my visual
8 and not in my audio, please, so that would make it
9 a little better.
10 The first question we heard was from
11 Janelle Palacios. Janelle, I'm going to
12 paraphrase what you said, which is as follows:
13 For the communities that go through the
14 very painful loss of loved children, especially in
15 smaller communities and tribal communities, are
16 there actions to help communities through this
17 pain and what should we be considering in the
18 future around the disproportionate impact or the
19 special and unique impact in smaller communities,
20 and particularly tribal communities.
21 Janelle, did I do justice to your
22 question? Is there anything you want to add? And

1 I'd like to ask if either Julie or Sara, Dr.
2 Kinsman, or Julie Zaharatos might be able to
3 respond to that part of this data system.
4 SARA KINSMAN: Sara Kinsman here.
5 Janelle, that is a wonderful question. And it is
6 on -- the center is working really closely with
7 six tribal entities who are trying to do this
8 work. It's particularly, I want to say
9 particularly difficult for tribal entities to do
10 this work because of some of the law enforcement
11 issues that get involved.
12 So, they've been working with the Casey
13 Foundation, the Casey Family Foundation, to really
14 develop protocols and ways of protecting the
15 community so that the communities can talk through
16 the work and then decide how within the community
17 changes can be made.
18 So, I think that for those communities it
19 takes -- it's so fascinating that folks, you know,
20 tribal entities will reach right directly out to
21 the center rather than go through the stakes.
22 They feel more comfortable doing that. So, we

1 have some connections that way and then some
2 connections that are coming through the state.
3 And I would be happy to come back in a
4 year or so and share with you more information
5 because those really are in development and are
6 different depending on which nation we're working
7 with.
8 So as far as smaller communities, you
9 know, very small communities have a harder time
10 doing CDR within their community, so they may be
11 part of a state community, or in Pennsylvania,
12 where I'm from, a smaller community would reach
13 out to the Philadelphia Child Death Review, or
14 Fetal Infant Mortality Review or for abuse, the
15 Act 33. And we would actually join with them and
16 do a shared discussion to really help them, you
17 know, do some of the work.
18 For example, Delaware has incredibly
19 strong child death review and FIMR review
20 committee, and then sometimes it would be helpful
21 for us to join forces a little bit.

1 So, the other thing, I think, that is
2 really, really important, and I don't think that
3 we have enough supports to do this, is that every
4 time we reached out to do maternal interviews, now
5 our maternal mortality team did not do interviews.
6 I think we were, you know, per Maria, through CDC,
7 we did not do them.
8 But for the FIMR interviews, it was a
9 trained social worker who was also skilled in
10 bereavement. And when I say skilled, I mean
11 really skilled in bereavement and would meet that
12 parent wherever they wanted to meet, at their
13 home, anywhere that was convenient for them, with
14 whomever they wanted to have present.
15 And the idea was to make the discussions
16 also a healing opportunity so that folks could
17 heal. You may know that the Baltimore FIMR was
18 able to have PSAs from parents who have lost their
19 children, and that's an incredible way for people
20 to have such a tragic loss be transformative for
21 themselves and for their community. So, we tried
22 to work in that way.

1 MAGNA PECK: Thank you very much, Dr.
2 Kinsman. Julie, is there anything you want to add
3 to that in our end response to Janelle's question?
4 JULIE ZAHARATOS: I don't have anything to
5 add, thank you.
6 MAGDA PECK: And Sara, I want to thank you
7 for layering in, again, and integrating the
8 conversation between this and the -- the interplay
9 between this morning's powerful presentations and
10 your comment in the chat now, which if you could
11 just summarize if people don't have access to the
12 chat as a powerful one to integrate. Would you be
13 willing to surface that?
14 JANELLE PALACIOS: Sure. The comment I
15 wrote is basically that law enforcement on tribal
16 reservations is multilayered and complicated and
17 especially if you have non-indigenous people
18 living on the reservation. Tribal law enforcement
19 doesn't have jurisdiction on them. So, you have a
20 local town community or county law enforcement
21 that is non-indigenous run.

1 And so, you have that lawyer and then the
2 tribal law enforcement. And then in addition you
3 have state law enforcement. And then after that,
4 depending on what kind of crime is committed, the
5 FBI is the sole law enforcement that -- the
6 jurisdiction that is involved. It's very
7 complicated. It is very messy. I'm sure many
8 things are missed, there are many missed
9 opportunities for appropriate collection of
10 information and evidence, and because of the
11 system that we have in place, which is not
12 necessarily ideal, but it does -- it does
13 recognize sovereign nations as tribal nations with
14 their law enforcement and governing, self-
15 governance and self-jurisdiction.
16 You know, it goes back to the maternal
17 deaths, you know, what's labeled a homicide,
18 what's labeled a suicide and how they're dealt
19 with and in addition to like the murdered and
20 missing people in those communities. It's very
21 complicated.

1 MAGNA PECK: And something for us to be
2 hugely mindful of, and we will take that
3 consideration into our data and research to action
4 workgroup so that we can rise up the very specific
5 issues in Indian country.
6 And yes, we're glad, Sara, to hear in a
7 year, but we're not going to wait for a year,
8 where in all honesty there is an urgency, and so
9 we will do our best to see what recommendations
10 may be coming forth.
11 And towards that end, I had asked Tara,
12 who had her hand up yesterday, but I did not get
13 any written comment, but before that, my last
14 piece from me is we want to have these data,
15 qualitative and quantitative community-driven data
16 that come from these sentinel health review case
17 review systems that are mature. And we want them
18 to be useful and used and aligned.
19 So, I was wondering, Julie and Sara, you
20 know, we have the FIMR and it integrated with CDR,
21 and now we have a unique and special system for
22 maternal mortality review, and this -- SACIM has

1 worked hard to look at DIAD data and how to
2 integrate the two.
3 So, coming from CDC and HERSA, I was
4 wondering how do you see the alignment and
5 interplay between these two potent and powerful
6 systems that are out there in a life-course DIAD
7 way, and is there anything that SACIM can do to
8 further encourage the maturation and integration
9 of the data. And Julie, would you start?
10 JULIE ZAHARATOS: Sure. And then you for
11 that. And I will say, and Sara and I have talked
12 about this, too, but it can be difficult to align,
13 for example, FIMR and maternal mortality review
14 recommendations for the same year, or even the
15 maternal and infant death that occurs on the same
16 day because of the timeline and varying capacity,
17 jurisdiction, and existence of the reviews.
18 So, I think that that is one
19 consideration that you might want to consider as
20 you're looking at your recommendations. You know,
21 most MMRCs are at the state level, not at the
22 local level, so that's quite different. But

1 anyway, I'm looking forward to additional thoughts
2 that others might have on this.
3 I will say that in our worlds that self-
4 care is a big thing, self-care for the staff that
5 read through these qualitative analyses and the
6 reviewers who are community members, or
7 clinicians, or whatever background they may have,
8 that self-care is really important. We don't want
9 to be burning out the folks that are spending the
10 time to do this really important work.
11 So maybe coming together on resources for
12 staff and reviewers, and also maybe thinking about
13 how to evaluate these sorts of sentinel reviews.
14 MAGNA PECK: Very helpful. Thank you.
15 Sara, anything you want to add to that?
16 SARA KINSMAN: I would only -- I agree
17 completely with Julie. I think the other thing
18 that may be very important to think about is that
19 the recommendations that come out, especially if
20 they're related to some of the social determinants
21 of health or if they're related to how people
22 experience healthcare, experience racism,

1 experience classism, all of the ways that
2 healthcare is unpleasant for folks, those types of
3 recommendations, I think, might overlap. I think
4 about how difficult it is for people to get the
5 help they ask for from mental health and health
6 systems, and I think that the maternal mortality
7 review will shine light on that, and those
8 recommendations will be helpful.
9 And then in our child and FIMR, as you
10 know, FIMR is totally de-identified, so we can't -
11 - in those reviews could also give general ways
12 that we can improve systems of care. So, I hope
13 that's helpful.
14 MAGDA PECK: Very much so.
15 LINDA BANE FRIZZELL: Before you move to
16 the next person, may I make a comment on what
17 Janelle was talking about?
18 Is anybody familiar with the 280 Law?
19 They kind of dump their -- there are seven or nine
20 states, I forget now, that they kind of dumped law
21 enforcement on the tribes, and no money followed.
22 So, it's kind of a mess, and tribes are irritated,

1 as they should be. But in the State of Minnesota,
2 which is a 280 state, if you're arrested or picked
3 up or whatever, if you're an enrolled member, you
4 have a choice to go to tribal court or to county
5 court. The other non-Indians, of course, are all
6 traded off to the Sheriff's Department. But that
7 really kind of messes things up.
8 And then secondly, I didn't get a chance
9 to talk about misclassification. but even then,
10 if you're arrested or whatever, there's a
11 misclassification. And I've seen in hospital
12 discharge data misclassifications of up to eighty
13 percent. So, you got to be careful with the data.
14 MAGDA PECK: Thank you for that insight.
15 I think the recommendation that Janelle is putting
16 about if we're going to be doing maternal fetal
17 infant child death reviews involving American
18 Indian, Native Americans and in Indian country or
19 in urban settings, the ability to take the
20 information we got from Dr. Palacios today and
21 bring it forward as an essential grounding for the
22 reviewers themselves would be another

1 recommendation to consider at the programmatic
2 level to strengthen that capacity.
3 LINDA BANE FRIZZELL: There's a way to do
4 that because we did it. Because the state's data
5 was so skewed that we actually got permission to
6 go to the Social Security Administration, and
7 everybody that -- they're really good about it,
8 the nurses are good about getting new infants
9 social security numbers. And once you have that
10 enrolled card, you can double-check with social
11 security. That gives you an accurate account of
12 how many different people are actually using
13 because that's a permanent record.
14 So, anybody that uses a tribal facility,
15 poof, they're flagged as being an Indian person.
16 MAGDA PECK: Well, thank you, Dr.
17 Frizzell, we really appreciate that insight.
18 We'll be using you as a resource as we move
19 forward. So, thank you for making that offer.
20 I did not see a question from Tara, and I
21 know we are at time. I'd asked her to post in the
22 chat or let me know, so I do not want to cut you

1 off, Dr. Lee. I want to also respect, Dr.
2 Ehlinger, your schedule for today. And so, thank
3 you.
4 TARA LEE: I posted it in the chat
5 yesterday, but I can maybe follow up directly with
6 Dr. Kinsman with that question. We don't have to
7 -- I know we're short on time. So, I'll just --
8 but I did post it in the chat yesterday, but I
9 have no problem following up with Dr. Kinsman.
10 MAGDA PECK: Thank you so much. We've
11 been trying to track that, and I didn't want to in
12 any way miss the opportunity to hear your
13 question. So, we'll make sure that it gets
14 followed up.
15 The bottom line for the data research
16 action workgroup is that we have extraordinary
17 data that are being generated that may help us in
18 much closer time have impact on policy and
19 program.
20 We also recognize the extraordinary gaps
21 in those data and other data that we want to work
22 to fill. And the more we're aware of what

1 strengths and blind spots and weaknesses are
2 there, the more we can make recommendations for
3 data to lead to action.
4 With that, I thank you for the additional
5 time and I return back to Dr. Ehlinger.
6 EDWARD EHLINGER: All right, thank you,
7 Magda. And before Sara and Julie leave, I have a
8 question also, because it leads into what I'm
9 going to be talking about, narrative.
10 You're messaging to -- you know with the
11 data that you have; I know you message to
12 healthcare providers and people in the human
13 services area, and you message to people who
14 experience these things. But as I mentioned
15 yesterday, there are a lot of non-medical factors,
16 a lot of social issues that really impact or
17 causing these child and infant maternal deaths.
18 And how do you message to the general
19 population about the issues that they have some
20 control over that actually impact the deaths of
21 moms and babies and children?

1 SARA KINSMAN: I'm happy to -- Julie,
2 do you want me to go first? I don't know if Julie
3 is still here.
4 JULIE ZAHARATOS: You can go ahead.
5 SARA KINSMAN: Okay. So, in the
6 Philadelphia work what we did was, you know, safe
7 sleep recommendations are very difficult because
8 you're asking a family to do three behaviors
9 simultaneously and never make a mistake on those
10 three behaviors.
11 So, we took the American Academy of
12 Pediatrics' seventeen behaviors for safe sleep.
13 We reduced them down to the three most common ways
14 that children die in the City of Philadelphia. We
15 had something called charts where we reviewed our
16 data on what was associated with infant sleep-
17 related deaths, and we created language that we
18 had all the in-home providers use. We had foster
19 support folks use, foster parents use, and it was
20 very, very, very simple, and we also used images
21 that described the pictures with -- the grade
22 level, by the way, was third grade and under. And

1 then we used pictures of families from our Healthy
2 Start families who volunteered to let us come into
3 their homes and take pictures of them in bed in
4 their jammies. And then we also used that to
5 create an opportunity for people to call the
6 Healthy Start team and folks would go to the house
7 and help the parents and family or foster family
8 set up a safe sleep environment.
9 And we used the data -- we said we were
10 using the data from our child death review,
11 because this is how babies in our city die, and we
12 do not want your baby to die. And those are the
13 things that we know, you're trying to keep your
14 baby safe, this is how you'll keep them extra
15 safe.
16 And so that was one way we did it. We
17 also did a breastfeeding campaign, which was
18 Breastfeeding is Normal, and was able to have
19 incredible visual images of African/American women
20 in our city, also Healthy Start participants, you
21 know, just be breastfeeding and just be okay with
22 it. That was interesting because people were

1 uncomfortable with that. They weren't as
2 uncomfortable with the safe sleep messages.
3 And I'll send it to you, Julie.
4 EDWARD EHLINGER: Julie?
5 JULIE ZAHARATOS: Oh yes, thank you so
6 much. So, you know, I heard you say message in a
7 way that the people who are affected can make the
8 change. And I will say that many --
9 EDWARD EHLINGER: Well, people -- too
10 often we focus on the people who are affected and
11 make it an individual issue.
12 JULIE ZAHARATOS: Okay.
13 EDWARD EHLINGER: I want to say this is a
14 societal issue. How are you getting this
15 information out to the general population to say
16 we need to change housing policies, we need to
17 change education policies, we need to change
18 economic policies, we need to change violence
19 policies, how do you use those data to actually
20 change the narrative about what creates health?
21 JULIE ZAHARATOS: That's great. Thank
22 you. Thank you for clarifying that because yes,

1 we're seeing that many of the recommendations are
2 actually in at the system level, right? So just
3 as you were saying, we work hard with the state,
4 MMRCs to make our recommendations actionable. Who
5 should do what, when? They should not include
6 jargon. They should use clear language where
7 stakeholders can see themselves and pick it up and
8 take action.
9 So, for an example that you were just
10 saying, that perhaps on preventing maternal
11 overdose deaths, if all of the treatment
12 facilities in your state don't accept women with
13 children, then maybe that's a barrier.
14 And so, say the state's residential
15 treatment facilities should accept women and their
16 children with them for -- you know, that could be
17 an actionable recommendation.
18 So anyway, I hope that that's helpful and
19 answers your question.
20

1 **NARRATIVE DEVELOPMENT—HEALTHY MOTHERS, HEALTHY**
2 **BABIES, HEALTHY SOCIETY**
3 EDWARD EHLINGER: Very good. Because I do
4 want to raise the issue because that's what I
5 really want to talk about in this little segment
6 that I have in terms about narrative. And I think
7 it's really interesting that today is the
8 anniversary, September 22nd, 1862, President
9 Lincoln issued the Emancipation Proclamation. You
10 know, that stated that slaves would become free on
11 January 1st, 1863.
12 And despite what most people think, the
13 Emancipation Proclamation was really limited in
14 its scope, and it really didn't do everything that
15 most people think, but it did one thing, it
16 captured the hearts and the imagination of
17 millions of Americans, and it fundamentally
18 changed the character of the war.
19 It changed the narrative about the civil
20 war from a struggle to preserve the Union to one
21 focused on ending slavery. And Lincoln knew that,
22 that the change of the narrative was critical
23 because he said, quote, public sentiment, or

1 narrative is everything. With public sentiment,
2 nothing can fail. Without it, nothing can
3 succeed. Consequently, he who molds public
4 sentiment goes deeper than he who enacts statutes
5 or pronounces decisions.
6 He makes statutes and decisions possible
7 or impossible to be executed, really stating the
8 fact that unless you get public sentiment, unless
9 you capture the public narrative, you're not going
10 to be able to make changes.
11 And I added a couple of other examples in
12 the -- of the power of narrative in the briefing
13 book. The article about Think Before You Drink,
14 challenging the narratives and fetal alcohol
15 syndrome disorder in Canada.
16 And that article shows how the narrative
17 about fetal alcohol syndrome spectrum disorder in
18 the indigenous community is really focused on
19 personal choice. If they just made the right
20 choices during pregnancy, this would go away.
21 And it totally negates the societal
22 inequities that created those conditions that

1 fostered the FASD. And they stated in that
2 article, the narrative, it said this narrative de-
3 politicizes FASD by conceptualizing settler
4 colonialism as a past event, ignoring ongoing
5 contemporary forms of settler-colonial
6 dispossession and resituating FASD within an
7 expert language that locates the solutions to FASD
8 within the affected individuals and communities.
9 And in so doing, these narratives legitimize and
10 contribute to perpetuating existing disease
11 inequities, prevent the formulation of policies
12 that address the very real and yet unmet needs of
13 FASD affected individuals and erase from the
14 public discussions about changes that could truly
15 affect FAST equalities at their root.
16 Really, they focus the fact that the
17 narrative is really keeping indigenous women and
18 indigenous communities from addressing that.
19 The other article that just came out in -
20 - well, published in the New York Times in August,
21 August 30th of this year, but the black mortality
22 gap in a document written in 1910, and it

1 highlights the fact that the Flexner Report, which
2 really revolutionized medical education, came
3 about with the stated purpose of improving the
4 quality of medical education.
5 And by doing this, Abraham Flexner, in
6 his report, blasted unregulated medical education
7 and urging professional standards to produce fewer
8 and better doctors. And it recommended raising
9 students -- you know, the requirements to get in
10 and they suggested that medical school should
11 adopt a northern city training model and that
12 states should bolster regulations and all of these
13 things that really changed medicine, and it
14 directly changed medical education.
15 As a consequence, however, you know, a
16 number of schools closed. I think what did it
17 say, more than half of the medical schools in the
18 U.S. and Canada closed, and seven of the nine
19 black medical schools closed. The only two
20 remaining were Howard and Meharry. And black
21 physicians were told that you can only -- should
22 only take care of black patients.

1 And from that narrative emerged the
2 vision of an ideal doctor. A white wealthy man
3 from a northern city and they controlled the
4 medical field into the hands of these physicians,
5 and that is carried on to today. So that
6 narrative is over a hundred years old, and it is
7 at the root of many of the problems that we've
8 been discussing over the last couple of days.
9 So, I think narrative is one of the most
10 powerful things we do. And I really want to see
11 if SACIM can actually help focus on narrative,
12 change the narrative.
13 I recognized when I was Commissioner of
14 Health that using my bully pulpit could help
15 change the narrative of what creates help and
16 really raised the issue of equity to a centerpiece
17 of what went on. And there were many other
18 factors, but I think we really had an impact in
19 raising the issue of equity.
20 And lately, I've been working on the
21 issue of changing the narrative about voting,
22 another huge public health issue. And I've also

1 been working with the University of Wisconsin
2 Population Health Institute which does the county
3 health rankings and healthy impart partners about
4 changing narratives related to racial and healthy
5 equity.
6 So, I want to reprise what I brought up
7 in April 2018 in this committee, that really, we
8 want to look at narrative as part of the SACIM
9 activity. I would like to actually create a SACIM
10 report, sort of like the Flexner Report that
11 changes the narrative about the importance of
12 mothers, babies, and families for both the short
13 term and the long-term success of our country with
14 the hope that this new narrative would help change
15 investment policies and public policies and this
16 would create a platform, I think, then for the
17 next iteration of SACIM to actually continue their
18 work.
19 So right now, babies and moms and
20 families don't have much power, even in the public
21 health world. Sorry, Michael Warren, the MCH
22 programs and state health departments are very low

1 on the organizational totem pole in state health
2 departments.
3 I really want to raise them up. I want
4 to raise NCH units up. I want to raise moms and
5 families up. And it's so important to the health
6 of our society that everybody says that should be
7 the first focus of policy and program change.
8 We made that recommendation to Secretary
9 Becerra, but we don't have the big narrative, the
10 public narrative behind that to force him to do
11 that.
12 So, I'm hoping to hijack some of the work
13 going on with the Population Health Institute and
14 I've recruited a fourth-year medical student who
15 is really interested in a narrative change, and
16 I'm looking for some other SACIM members to join
17 me over the next three or four months to lay the
18 framework of how we want to really advance that
19 whole narrative agenda.
20 **NEXT STEPS**
21 EDWARD EHLINGER: So that's what I'm going
22 to be asking for as sort of our next steps, which
23 then leads us into these next steps. How do we

1 want -- in the last three meetings that at least
2 seven of us and probably eight of us have, what do
3 we want to do to actually move things forward?
4 I'm hearing some things, you know, you
5 hear my push on narrative, but I've also seen, you
6 know, we're going to do some more work on
7 indigenous health. We need to do a lot more over
8 the course, coming up with some recommendations
9 next June around indigenous health.
10 I heard that we really need to do a lot
11 about financing, both in Indian country and in the
12 rest of the society, so I'm hoping we will do
13 that. I heard that we need a lot more about the
14 data, we need about the sentinel reviews, we need
15 to push those forward. So, I -- you know, those
16 are some things that are going, but I also don't
17 want to lose the expertise and the energy of other
18 members of SACIM who really are just anxious to
19 move something forward. So, I wanted to say are
20 there people who want to step up and do something
21 in these last, between now and next June to
22 actually make an impact in SACIM.

1 So, I'm going to open it up for some
2 conversation around that. And I -- like I said, I
3 shared with you last night what you had said at
4 our last meeting, and I want to give you another
5 chance to say I'm willing to step up and take that
6 on, or I want to join with somebody on the
7 indigenous health line, or I want to enjoin with
8 the data group, or I want to join with the
9 finances so that we can mobilize our energy and
10 actually move this committee forward in a really
11 powerful way.
12 So, opening it up for any conversation.
13 I shut down the narrative.
14 VANESSA LEE: Belinda, why don't you talk
15 about the workforce piece, just let's start with
16 your posting.
17 BELINDA PETTIFORD: I do think one of the
18 other parties -- I know you mentioned several
19 things and I appreciate that, but I do think we
20 need to include in this discussion how do we
21 diversify our workforce and what does it look
22 like, does that include doulas, community health

1 workers, and others? Does that include figuring
2 out how do we pay for individuals of different
3 backgrounds, individuals of color to make sure
4 they have access to become providers, and other
5 parts of the healthcare system?
6 Because it goes back to me, the issue of
7 making sure that families and individuals have the
8 options. Not everyone is going to think through
9 and want to look at racially concordant care, I
10 understand that, but for those that want it, they
11 should have that as an option.
12 So how do we diversify our workforce at
13 every level, or can I just limit it to some folks?
14 So that is part of the thing that I definitely
15 want to work on.
16 EDWARD EHLINGER: Yes. And a lot of these
17 things overlap. Certainly, indigenous health and
18 race concordant care and equity, I mean, they're
19 all overlapping and integrated. So, I thank you,
20 that is important.
21 And that was part of our recommendations
22 back in June. So, I think that is one of the

1 things that I want to make sure that we keep
2 moving forward, so thanks.
3 UNIDENTIFIED SPEAKER: I'll just speak up
4 real quick. You know, we heard from Dr. Kinsman
5 yesterday about one of the most common reasons for
6 infant death is congenital anomalies. And we know
7 that just with amazing advancements in science
8 that some of these congenital anomalies are
9 treatable before birth, both surgically and just
10 also with therapies that are available, something
11 as simple as, you know, women taking folate, you
12 know, prenatal folate, you know, just to help to
13 reduce the risk of spina bifida.
14 So, I guess I would like to give some
15 more attention to some of those advancements that
16 are available and that we know are saving babies
17 and were, you know, a better understanding, were
18 families made aware of these, some of these --
19 some of these advancements and treatments before
20 birth, and were they given an option to receive
21 them? I think we want to increase access to all
22 populations. And if they aren't getting access, I

1 think we need to discuss why, because there are
2 many cases where parents receive a poor diagnosis,
3 and I think a lot of times they feel like they
4 don't have many options. So, I think we need to
5 make it very clear that there are some very real,
6 treatable options that can help save the baby.
7 So, I would like to see more attention
8 and I would be thrilled to be involved and be
9 given time to discuss that further at one of the
10 future meetings.
11 EDWARD EHLINGER: Yeah, excellent.
12 So, the way I functioned in the past is I tried to
13 work the presenters up through the various
14 workgroups so that it gets vetted through there.
15 So, I know, Tara, you're on the health
16 services workgroup with Steve. That would be a --
17 I think coming with a recommendation, here's who
18 would like to bring on to one of our meetings and
19 these are sort of the questions we'd like that
20 person to address, you know, a presentation to
21 sort of frame it with that. And so, I would
22 suggest you work through Steve, you know, to get

1 that onto the agenda at one of our upcoming
2 meetings.
3 TARA SANDER: Okay, will do. Thanks.
4 JANELLE PALACIOS: Hi Ed. I am very
5 interested in helping you with -- with the amount
6 of time that I have to just help reframe the
7 narrative. And that is something that I have said
8 from the beginning of 2018, kind of like what is
9 our comparative hand washing, and from the
10 beginning, I have talked a lot about big cultural
11 changes and norms.
12 And if we are going to -- we are
13 basically putting Band-Aids on problems that exist
14 right now, and how are we going to prevent these
15 problems from occurring in the future. It's taken
16 a few hundred years for black and indigenous
17 people to have these horrific outcomes right now
18 and given that time is flowing and that it moves
19 forward, and things haven't changed for many
20 people, that there is still a large kind of
21 marginalization, it's going to take time to then
22 change and effect change that, you know, my great-

1 grandchildren will not experience the same sort of
2 obstacles that my family has experienced.
3 So that is something that I've always
4 wanted to do, and I've said from the very
5 beginning, so I would like to lend my voice in
6 that aspect.
7 EDWARD EHLINGER: Yes.
8 UNIDENTIFIED SPEAKER: I know there were
9 points made about diversifying the workforce, but
10 we sort of haven't with the workforce that we
11 have. So, I hope that we don't forget that,
12 although it's important for us to think about
13 other health providers, including doulas and
14 midwives, that we don't forget that we are
15 woefully short in terms of the diversity of our
16 current healthcare system and that we don't, you
17 know, lose that message that we also heard
18 yesterday in terms of the need to increase the
19 diversity of our existing healthcare workforce.
20 And you know, in terms of concordant
21 care, you know, I had the personal experience of
22 practicing pediatrics in the military, which is a

1 very diverse group of both healthcare providers
2 and patients, and I would say there is something
3 to be said about diversity allowing for shared
4 experiences, so that you can have still concordant
5 care but you can also have diversity in terms of
6 how we help collectively people to understand the
7 issues that challenge, you know, within a diverse
8 population.
9 And another thing just thinking about,
10 and I think Janelle sort of alluded to it and so
11 did others, that it is important for us to rethink
12 what we perceive as healthy practices based on
13 evidence, but also in the context of history.
14 You know, breastfeeding is a good
15 example. And for some African/American women,
16 there is a history there in terms of being, you
17 know, nursemaids and it may be that it is not
18 necessarily appealing a practice, and so how do we
19 think about these public health messages? Also,
20 with regard to safe sleep, how culturally
21 appropriate are we being in terms of safe sleep
22 messages, particularly for American Indian and

1 Alaska Native populations in terms of taking the
2 context of the solutions collectively?
3 So, I think we need to think about that.
4 We've also seen, you know, issues also around, you
5 know, how our messaging are areas around
6 behaviors, and really thinking twice about that
7 and not taking a majority lens on it over.
8 EDWARD EHLINGER: Excellent. Any other
9 thoughts? Magda?
10 MAGDA PECK: So, a couple. First of all,
11 thank you, Ed, for framing the narrative piece,
12 which you know I have passion about and will be
13 working with you on.
14 I am delighted to see the growth of the
15 interview component, that direct listen to the
16 story component, to hear the lived experiences in
17 real-time that is emerging further in maternal
18 mortality reviews is now strong, and fetal infant
19 mortality reviews and the notion of informing that
20 narrative with her, his and their voices.
21 And so, I'm going to continue to push for
22 strategic storytelling to be as both shaping the

1 story and telling the story and who gets to tell
2 that story to whom in a way that is both strategic
3 and sacred, will be a way to inform the narrative
4 work.
5 That's what in this time of
6 hyperpolarization can find common ground when we
7 have not lost our humanity or our empathy in times
8 that backs are against a wall. So that's one.
9 A second, we heard yesterday from one of
10 our speakers that even capturing information on
11 race of provider is not uniform. We have to be
12 persistent and relentless in pushing for race-
13 specific information around workforce in addition
14 to larger population health data.
15 And it's given the push back that is
16 happening in many states where the conversation
17 around equity and race and racism is being
18 suppressed, this is our chance as SACIM to be bold
19 and direct and pushing about that data being used
20 for action and not being withheld, judged, or
21 pushed down.

1 So, I really am going to ask us from the
2 data side to not only push the stories to inform
3 narrative but to push hard on the data that we
4 need to be able to address the systems of
5 oppression that are around.
6 So let me stop there and just say you can
7 count on the dated action piece but I'm going to
8 work hard on our helping to elevate the data that
9 are missing, the data that are misclassified, the
10 data that are suppressed in a way that's not
11 letting us tell the full story about women and
12 children, families and fathers, and we get to be
13 able to assure that those stories are told.
14 Thanks.
15 EDWARD EHLINGER: Yeah, and that reflects
16 in the fact that in our culture things are very
17 horizontal and linear and we think that worldview
18 affects narrative, which then affects the stories.
19 But in the indigenous world, as we heard
20 from Wakinyan this morning, it's all circular that
21 yes, world view affects narrative that affects
22 stories. But stories also impact narrative and

1 also impact world views. So that -- all of those
2 are necessary, so thank you for that.
3 MAGDA PECK: I want to just tag on one
4 last piece and that is that the linkage, given how
5 much we're working within the maternal and child
6 health space now around case review and sentinel
7 events, and I will look to draw on my colleagues
8 to ask within the housing sector and housing
9 security, what are the case reviews that happen
10 within food and security, what are the case
11 reviews that happen within economic instability
12 within immigration, within the other related
13 social environmental conditions that we're looking
14 at?
15 We can't be the only ones that are
16 knocking on doors and asking folks to tell their
17 story. So, we have a responsibility to make sure
18 that as we go to the qualitative and the story
19 part, that we're not burdening the same folks with
20 too many knocks at the door, and we're looking at
21 the interoperability and the intersectionality of
22 data to action and lived experience.

1 So, I'll look forward to seeing how all
2 of our ex-officio members from other sectors who
3 are here to help us look at these data in a
4 horizontal way, not just in each of our MCH and
5 other worlds. It's our duty to do so to not
6 violate the spirit and hearts of the folks who are
7 working to serve. Thank you.
8 EDWARD EHLINGER: All right, Colleen.
9 COLLEEN MALLOY: Hello. So back to
10 provider burnout. I'm at my job three here, so I
11 apologize for the background, I'm in my car.
12 But I -- you know, I've been on this
13 committee for -- I'm one of the ones nearing the
14 end, so I'm probably getting maybe more, I guess,
15 bold -- I don't know if bold is the right word or
16 not, but you know, when I began on this committee,
17 and I think we all talk about elevating babies and
18 mothers, families, that's all part of the
19 narrative that we're trying to impress upon
20 people.
21 So, I think, you know, you're saying we
22 have a low spot. I don't know if totem pole is

1 the correct terminology. Maybe the American
2 Indian folks could help me, that's probably not
3 correct to say, but I think you said that we put
4 women and children on the low end of the totem
5 pole in different sectors of society. We're
6 trying to change that narrative.
7 So, I a hundred percent agree with that,
8 and I hundred percent agree with elevating
9 pregnancy and its importance and the role that
10 pregnant women play and how they interact with
11 society, trying to go to work, trying to raise
12 families, trying to, you know, educate their
13 children and all that.
14 I think the bold part of it for me, I
15 think, is that you know, on one hand, we're saying
16 we want to do all this and the other hand, you
17 know, we need to support pregnancy to the point
18 that if there's a difficult pregnancy we recognize
19 that, you know, in America like it's one of, I
20 think, seven countries that allows abortion up to
21 the ninth month of pregnancy.

1 So, it's kind of -- it's like split
2 hypocritical position to take, we're elevating
3 mothers but yet for no reason, it doesn't have to
4 be medical, for any reason at all you can have an
5 abortion up to the ninth month of pregnancy.
6 So, I feel like that's really a dichotomy
7 in terms of how we look at pregnant women, and
8 that definitely from an equitable piece affects
9 what we're offering black mothers more across the
10 board than other parts of society.
11 So, you know, if they're in a difficult
12 social situation, here's what we're offering, you
13 can kill your baby. So that, for me, that's where
14 our ideological split occurs, because it's not
15 fair to them to offer that as a solution. It's
16 not fair to any family to offer that as a
17 solution.
18 So, when I think of elevating pregnancy
19 in women and families, for me, if we allow for any
20 reason in this country, abortion up to the ninth
21 month, that is like -- doesn't jive. It, like,
22 doesn't make any rational sense to me.

1 So, I think that, you know, part of this
2 committee has to keep babies in the forefront, and
3 I have always said that. And there is an
4 interesting speaking that I think we should have
5 on that actually links previous surgical abortion
6 history with preterm birth, which as we know is
7 related to increased infant mortality.
8 So, if we're offering certain groups of
9 society, certain racial groups of society more
10 abortion and therefore more preterm birth, and
11 therefore they have increase infant mortality, we
12 have to at least -- you know, we can agree or
13 disagree on that part of it, but we have to at
14 least look at that data because it's out there.
15 And maybe take a step back and say this isn't good
16 for these families. This isn't good for these
17 women. This isn't good for the fathers.
18 So, I think we have to be honest when
19 we're having these discussions and at least like
20 what I would recommend for one of the next
21 meetings is to listen to one of the people that
22 have presented or published papers on the link

1 between surgical abortion and prematurity. It
2 should be at least heard so people can then, you
3 know, make decisions on their own, and I think
4 that that in terms of -- it's hard for me to
5 elevate women and children when we're only
6 starting on, you know, the day the baby exits the
7 birth canal.
8 Like it's -- you know, all along we're
9 kind of pushing on the importance of the social
10 situation and nutrition and the home environment
11 and all that while she's pregnant, so that should
12 mean something.
13 And so I think that this is under the
14 guise of, you know, I'm just being bold because
15 I'm on my exit -- I'm on the launching pad, so I'm
16 just going to get it all out there and that's kind
17 of how I think like if we're going to really
18 appreciate women and babies, we have to appreciate
19 that whole practice (inaudible) little bits and
20 pieces that we want to appreciate of it. And I
21 guess I agree to disagree. I have no problem with
22 (inaudible) no problem at all, but I think at

1 least we need to hear other sides of it and like
2 how people kind of make that connection.
3 So that would be my goal before I leave
4 is at least to have people listen to some other
5 perspectives that would connect like the violence
6 of that, you know, situation for a pregnant woman
7 to be in to have to face that question of, you
8 know, am I going to keep this baby or not keep
9 this baby. Like those are huge social situation
10 that affect different parts of society differently
11 and I think that there's ramifications of it that
12 we probably should address.
13 EDWARD EHLINGER: You raise a lot of good
14 points. I think there is a lot of misinformation
15 and a lot of ignorance about information, and I
16 think it would be good for us to really look at
17 the objective data related to abortion. I have no
18 problem with looking at the objective data, you
19 know, whether or not related to preterm births,
20 and the birth outcomes and you know, and related
21 to the psychological impacts and all those things.

1 And I would suggest, and I'm putting
2 Wanda on the spot, I would love, Colleen, if you
3 could help us raise some questions, what are the
4 data that we should be looking at? What are the
5 questions that we should be asking that we could
6 actually look at some of the data to, you know,
7 give some credence to that, and then frame that so
8 that we can have a discussion about the actual
9 data and its impact on mothers and babies related
10 to termination of pregnancy?
11 COLLEEN MALLOY: Okay, thank you.
12 EDWARD EHLINGER: Wanda, would you be
13 willing to work with me on trying to raise --
14 WANDA BARFIELD: Yes. In terms of timing,
15 also it might be good to look at upcoming data,
16 which we're currently working on in terms of the
17 surveillance reports. So yes, I'm happy to follow
18 up with you on that.
19 EDWARD EHLINGER: Because as I
20 mentioned at the beginning, I raised the question,
21 ideologies don't get us anywhere. I mean, we all
22 have them, but we really need to focus on the

1 data, the objective data, both qualitative and
2 quantitative. I mean, they're both -- like the
3 stories, the lived experience are real data, and
4 we need to have those along with the very
5 objective data. So, I think that's where we look
6 at those with the whole notion of how do we do
7 what's best for moms and babies in society.
8 UNIDENTIFIED SPEAKER: And Wanda, we can
9 help from the population health centers as well if
10 you need.
11 EDWARD EHLINGER: All right, so I've got a
12 couple of comments here before we close because
13 we're actually at time, but I'll beg your
14 forgiveness for a few minutes over. Belinda.
15 BELINDA PETTIFORD: Yes, I would just add
16 into the conversation that we also need to look at
17 reproductive health in general and reproductive
18 life planning and pregnancy and cleanliness so
19 that an individual has access to what they need to
20 become pregnant when and if they choose to be
21 pregnant.

1 So, I think a lot of times we go to
2 abortion, and we've not talked about what her
3 options were before then. I mean, I look at some
4 of the legislation that is -- in my own state we
5 recently approved legislation around pharmacies
6 now being able to dispense contraceptive methods.
7 And so, what are we looking at that's
8 more broadly looking at reproductive health in
9 general and making sure that's part of a
10 discussion?
11 EDWARD EHLINGER: Excellent. Good. And
12 Lee.
13 LEE WILSON: Yeah, hi folks. I want to be
14 very clear about the level to which we're
15 transparent here in these discussions because I
16 think Colleen, you raised a number of issues that
17 you are interested in having explored and
18 discussed. Others have raised them in the past as
19 well.
20 I don't want there to be the perception
21 that certain things are raised, and then not
22 discussed and other things are just sort of pushed

1 through because they're acceptable for the
2 committee here to be talking about.
3 So for purposes of just openness and
4 transparency here, I'm going to ask Colleen if you
5 have a couple of key questions that you'd like to
6 be answered or topics that you'd like to be
7 addressed, that either you put them in the chat or
8 you send them in an email to Vanessa, or to me or
9 to Ed so that we have them for the record, and we
10 can be very clear about what is being asked and
11 what we're responding to and creating discussion
12 around.
13 Because I think, as you said Colleen, you
14 feel maybe a little embolden because you've got a
15 few more sessions left with us or not. I don't
16 want the committee to feel like they can't say
17 what they want to say as experts because they are
18 new to the committee or because they're at the end
19 of the committee, but this should be an open and
20 free conversation about real topics, mindful of
21 the fact that we may discuss it for a couple
22 meetings and then say we're in agreement or

1 disagreement on these topics and then moving on to
2 something else.
3 But for Colleen or Belinda or anybody
4 else, please make a record of these topics that
5 you're interested in us pursuing in the future so
6 that we're sure that we get to them, and so that
7 we can show to whoever is looking that we are
8 being open, transparent, and considerate of all
9 viewpoints here.
10 EDWARD EHLINGER: Thank you, Lee.
11 UNIDENTIFIED SPEAKER: I just want to just
12 add real quick, I just think this conversation is
13 incredibly timely. I mean, there is no --
14 everybody knows that Texas just passed their
15 heartbeat law. The Dodd's case is going to be on
16 the horizon for Mississippi arguing whether
17 babies' previability (sic) should be protected
18 against abortion.
19 So, I do think, just kind of going back
20 to Lee's point that I think this is incredibly
21 timely to have this discussion and I would be
22 happy to participate in the discussion as well and

1 provide any data, but -- because I do work. I
2 mean, there's no surprise, I work at a think tank,
3 and we look at the data every day and we have
4 highly qualified professionals. So, if you need
5 any resources, you can ask me, but I'll be sure to
6 contact Colleen and provide ones that I know are
7 solid and very reputable.
8 EDWARD EHLINGER: Okay, excellent.
9 All right, what I want to do to end is
10 just go around and have each of you just give one
11 takeaway from this meeting over the last two days,
12 which was a powerful two days, at least from my
13 perspective.
14 So, I will look at my screen, Tara,
15 what's your takeaway from this meeting?
16 TARA SANDER: What do I take away from
17 this meeting? I can tell you that I learned a lot
18 as always, and I really want to thank the SACIM
19 members that took the time to put together
20 sessions.
21 I learned a lot about Native Americans.
22 I, myself, my great-great-grandfather is actually

1 a hundred percent Native American. And so, I
2 learned so much, and so I thank you, Janelle, for
3 taking the time to put together the session.
4 I thank Magda for you also putting
5 together -- just everybody that participated, I
6 learned a lot.
7 My overall take is that this was just --
8 you know, we've kind of -- we've closed the door
9 on the recommendations to the Secretary for now
10 and we're kind of thinking of new ideas. And so,
11 I guess my takeaway is that we're just kind of
12 starting a new chapter and I think we're -- that's
13 really all I can say right now. We're learning a
14 lot of new things and I'm excited to just see
15 where we're going to go in the future.
16 EDWARD EHLINGER: All right, Janelle.
17 JANELLE PALACIOS: As always it feels like
18 we continue down the rabbit hole. There's just so
19 many more layers to this -- to these issues. But
20 what I was most impressed with, definitely was the
21 discussion on, again, the lack of data that we
22 have.

1 And then the data that we do have, you
2 know, for example, Dr. McDade's presentation was
3 just an eloquent summary of what we know to date
4 on race concordant care or just having choice and
5 listening to people.
6 And I did not know it was as broad and
7 extensive as Mr. McDade had shared. And so, I was
8 really appreciative of what I've learned.
9 EDWARD EHLINGER: All right. Lee. Lee
10 Wilson.
11 LEE WILSON: Oh, I learned a tremendous
12 amount from the committee members about the depth
13 of knowledge and experience that they bring to the
14 table and the motivations that they bring. And it
15 was really helpful for me, sometimes as I spend a
16 lot of time on the bureaucratic aspects of this
17 job and making sure contracts are awarded and
18 grants are written in ways that check all the
19 boxes and still try to make change. I'm tying
20 that back to the history.
21 Janelle, I worked with tribal groups on
22 the ground for a dozen years early in my career,

1 and just on the reservations looking at some of
2 the difficult situations and knowing that many of
3 those situations have not changed in the decades
4 since my work there is really staggering to me and
5 what a different world it is from the world that I
6 step out of my front door on a daily basis reminds
7 me of why I'm in this work and why looking at it
8 from different perspectives around issues of
9 racial concordant care and the way people are
10 feeling about the services and care that they are
11 getting and that they need and that they deserve
12 is complex and will continue to be complex.
13 And so I'm just very appreciative of the
14 passion that all of you bring to this, and I'm
15 sitting here having sideline conversations with
16 folks about ways that we can videotape and capture
17 some of these discussions for posterity so that
18 when somebody goes onto our website and says what
19 is SACIM about, that it's not a, you know, a
20 mission statement, but they can actually click on
21 a thirty-second video clip of Janelle talking
22 about why it's important to her constituents that

1 she's representing, or to Ed, or to Tara, or to
2 somebody else. So, thank you.
3 EDWARD EHLINGER: Thanks. Magda.
4 MAGDA PECK: Thank you to my
5 colleagues and great gratitude, a lot learned.
6 Three quick takeaways. One is the reminder once
7 again that if you don't, won't, or can't count it,
8 it doesn't count, old adage.
9 And that there's a convenience to the
10 lack of data throughout all of my career of trying
11 to bring data to action. It has been what we
12 don't know, what is misconstrued, what is
13 misrepresented, misclassified, or just not there
14 that maintains a lot of the status quo.
15 And so, I want to just reinforce the
16 commitment that -- to assure that data are tools
17 for action, not for information alone.
18 The second is that history lives in our
19 bones and the bones of our grandchildren and that
20 without truly embodying in our work, cumulative,
21 historical trauma, and an agreed history that
22 cannot be erased, we will not get to the root

1 issues. We will just do one more Band-Aid. And
2 so, ripping off Band-Aids and Janelle and your
3 colleagues, thank you for, again, immersing us,
4 reminded me of the very first presentation with
5 Art James in terms of being able to say history
6 contacts knowledge base matters to put things in.
7 I will never forget about peanut butter and
8 spaghetti sticks, again.
9 And this is my last point. What we talk
10 about in MCH cannot be MCH. It has to be in the
11 context of commodities, food supply, housing
12 supply, and the like. And so, we tend to have
13 conversations among us about the MCH world. And
14 SACIM has to be able to shift more on the
15 horizontal and bring in voices outside of our own
16 families who are in the other sectors because
17 we're going to -- we can influence their worlds
18 far better if we have relationships with them.
19 So those are my three takeaways.
20 EDWARD EHLINGER: Steve.
21 STEVEN CALVIN: I really appreciated what
22 Magda put together with the colleagues, Julie, and

1 Sara, and I'm just particularly encouraged by the
2 fact that we've made such progress in the maternal
3 mortality and fetal and infant fatality reviews.
4 I mean, just when you see over the course of time,
5 it used to -- some states were good and some were
6 terrible, and I'm just encouraged by seeing that
7 kind of data collection.
8 So, I appreciate the work of the folks
9 in, you know, HERSA and CDC that do that kind of
10 work and then collaborate with states.
11 EDWARD EHLINGER: Paul Wise.
12 PAUL WISE: Thanks. Well, first I do want
13 to convey my appreciation to the presenters
14 yesterday and today. Really important work and
15 clarity of the challenge, but also opportunities
16 to make a difference.
17 I agree, we tend to go down rabbit holes,
18 but to make a difference and particularly to speak
19 about impact, we need to come out of our rabbit
20 hole. But as every rabbit knows, that conveys
21 some risk. And we do have choices that we will
22 need to make.

1 Basically, I think there are two. One is
2 to use our voice in solidarity with groups
3 throughout society to lend support on the issues
4 of deep, broad concern of justice, discrimination.
5 We can use our voice as a committee to provide
6 solidarity on those issues with others in the
7 political realm, scientific, virtually all.
8 But we also have the potential to be more
9 strategic in how we use our voice, very much
10 focused on a strategic impact related specifically
11 to our arena of expertise to draw strategically
12 upon our specific areas of legitimacy within the
13 field.
14 And that series of strategic arenas also
15 include our ability to pay close attention. We
16 can hold our professions, we can hold the
17 politicians, we can hold the administration
18 accountable for doing what we know would be best,
19 and not to let up. That is part of our strategic
20 capability in my view.
21 So, in service to solidarity essential,
22 but we also have the potential to use our more

1 strategic voice in service to the communities we
2 care most deeply about. I'll stop there.
3 EDWARD EHLINGER: Thank you. Belinda.
4 BELINDA PETTIFORD: Well, I enjoyed
5 every one of the sessions. I thought this was a
6 very well-planned meeting and all of the
7 presenters were excellent. And I think all of it
8 connected well to the work we're trying to do with
9 SACIM.
10 I think my bigger takeaway though is --
11 let me step back. I especially appreciate
12 Janelle's willingness to tell her personal story
13 so that the rest of us could understand better,
14 and hopefully, we did.
15 My bigger takeaway though is around what
16 David reminded us of at the beginning, is that
17 we've got to be persistent. And I think you've
18 done an excellent job, Ed, and just helping us
19 think through that narrative so that we can
20 actually have an impact positively on change. We
21 can't just focus on the small things; we really

1 have got to change the narrative of why we need to
2 do this work so that we can see improved outcomes.
3 I've worked in this field thirty plus
4 years. When I started in this field, we were
5 dealing with health disparities in perinatal
6 health, and I don't want to leave this field and
7 retire and we're still dealing with this on a day-
8 to-day basis.
9 So, I really appreciate your leadership
10 in moving us to that narrative.
11 EDWARD EHLINGER: Vanessa.
12 VANESSA LEE: I just want to say thank you
13 as well to all of you, the committee, and the
14 presenters and speakers we had. I also learned a
15 lot, as I always do, and I'm just really excited
16 to be the new DFO and looking forward to
17 supporting the committee in the next years. You
18 billed out your work. I've jotted down a lot of
19 the topics and am ready to help in any way I can.
20 EDWARD EHLINGER: Colleen. I hope you're
21 able to get on. What is your takeaway?

1 COLLEEN MALLOY: Yeah, I really enjoyed
2 all of the presentations. I thought that Indian
3 Health Service was very fascinating, I always
4 wanted to learn more about that. My husband also
5 is -- he's from Minnesota and is part Sioux,
6 although is very ignorant about his culture, so I
7 thought that was fascinating.
8 I guess my takeaway is a little bit when
9 we're trying to find concrete things to address.
10 What Steve said about the voucher, I mean, there
11 is a little bit of, you know, follow the trail of
12 the money, like is that something that we could
13 hit on more, because it even came up with the IHS,
14 like if, you know, they're struggling to find
15 services for people and it's all financially
16 related, so (inaudible) I guess my takeaway is
17 like maybe that's the way, to give the power to
18 the people or the power to the consumer that is
19 trying to navigate the healthcare system, which is
20 notoriously complex and difficult. As Steve said,
21 it's almost made to be complex because that gives
22 the people who run it the power, because the

1 people -- the consumers can't figure out heads or
2 tails, and for so long we didn't even have like
3 transparency on pricing and hospitals. So, I
4 think we finally have accomplished that.
5 But I think there is almost like
6 following the money trail, and maybe that's how we
7 empower people more if they can make their own
8 decisions and they can kind of like tailor what
9 they need more than us telling them what we think
10 they need.
11 So, I guess my -- I'm more of like, I
12 guess, an individualist but I think that was my
13 takeaway, is maybe that's the way you do it
14 instead of trying to like help people to empower
15 themselves more, but that was just my thought for
16 the past five minutes, so.
17 EDWARD EHLINGER: Thanks. Wanda.
18 WANDA BARFIELD: First of all, I just want
19 to -- the speakers were phenomenal, and I just
20 want to thank them for taking the time and really
21 sharing. And I also just want to acknowledge
22 Vanessa as you know, our new fearless leader, and

1 also thank David for the years that he served, in
2 addition to being on the committee, also deploying
3 many times during that time that he was on.
4 But just one thing to also take into
5 consideration for me, of the themes of hearing
6 voices rung out and I put some information about
7 hearing her in the chat, but I also wanted to
8 really thank the committee in its function of
9 providing input for PRAMS.
10 We're in the process of going into phase
11 nine, and your input was really very valuable. We
12 hope that at some point we can come back and share
13 what we've learned as we go through the whole
14 process, and we look forward to other
15 opportunities, not only just for CDC, but for
16 other federal agencies to be more specifically
17 informed around some of the work that we're doing
18 moving forward, sort of in its development.
19 So, I just want to thank you all for
20 that. And then in terms of just hearing from
21 mothers, you know, we are involved in trying to
22 understand more about the issue of stillbirths,

1 using the PRAM survey as well as doing some work
2 to better understand the response rates of women
3 who have experienced an infant death and finding
4 that there may be opportunities to better learn
5 from those experiences, where I think maybe in the
6 past we made a lot of assumptions about that.
7 So, thank you.
8 EDWARD EHLINGER: Thank you. And
9 Steve, Wanda did ask for the Dilbert quote, so if
10 you could give her the Dilbert quote that would be
11 good.
12 STEVEN CALVIN: Sure, I will.
13 ED EHLINGER: And my takeaway is sort of
14 bittersweet. The sweet part of this meeting is
15 that I am really impressed with the talent and
16 skills and experiences of the members of the
17 committee, both ex-officio and regular members,
18 just an amazing group of people.
19 The bitterness part is, I feel sad that I
20 haven't been able to actually tap into all of
21 those skills and expertise and bring them forward.
22 And some of you have stepped forward and have

1 really shown, but you know, I hate, like I said
2 last night in the -- I don't want to leave
3 anything on the table and I felt there was still
4 so much expertise and skill and knowledge that is
5 going to be left on the tables, but we've got, you
6 know, another ten months to do that.
7 And the other point is that you're all
8 really good storytellers in your own way. and
9 Plato said those who tell stories rule society,
10 and that's why I think the story that we can tell
11 from SACIM -- actually, I don't know if we can
12 rule society, but I think we can help our stores,
13 that if we can get them out in the right way can
14 actually change the narrative, which then can
15 change the overall story of how our society is put
16 together.
17 And so, I look forward to really some
18 additional conversations, trying to tap into your
19 skills and expertise and actually trying to make a
20 difference that I'm with Belinda, I don't want to
21 leave this world and having to say you know we

1 worked on this for fifty years and didn't make any
2 progress or made little progress.
3 You know, my grandkids and if I ever have
4 great-grandkids, are more important to me than
5 just being, you know, maintaining the status quo.
6 So, work with me, I'll work with you to
7 try to change the status quo for the better. So,
8 thank you all and I'll be back in touch as we move
9 on to the next steps. Peace.
10 MAGDA PECK: Thanks, Ed, for your
11 leadership. Thanks, everybody.
12
13 **ADJOURN**