Good morning and welcome to the 2017 CDC OMHHE Office of Minority Health and Health Equity in collaboration with the National Center for Bioethics and Research and Healthcare at Tuskegee University’s third annual Public Health Ethics Forum.

This year's focus is on Women's Health. And the theme is Optimal Health for Her Whole Life.

My name is Shonia Zollicoffer, and I will serve as the Mistress of Ceremonies for today. Today's forum is also streaming live. And for those attending virtually, please submit all questions and comments to OWH@CDC.gov. We will have that slide back up for you. Again, that email is OWH@CDC.gov.

So today we have a very, very robust schedule. So let us get started.

So allow me to introduce to you our first speakers which are Drs. Liburd and Tucker.

So Dr. Leandris Liburd is the Director of the Office of Minority Health and Health Equity here at Centers for Disease Control and Prevention. In this role, Dr. Liburd oversees the work of CDC's Office of Women's Health, Diversity and Inclusion Management and Minority Health and Health Equity. She is a respected public health leader, who has over the course of her career championed community health promotion, chronic disease prevention, community engagement, eliminating health disparities, and addressing the social determinants of health. She has worked in public health at the local, state, and federal levels, and has held a variety of leadership positions at CDC since joining the agency in 1987.

And our second speaker, Dr. Patty Tucker is the Director of CDC's Office of Women's Health. Dr. Tucker's career spans from clinician for women and children to consultant on evidence and practice-based strategies designed to promote healthy lifestyles and disease prevention domestically and internationally. Dr. Tucker has worked with the Center for Infectious Diseases in Zambia, Namibia Ministry of Health and Social Services National HIV Sentinel Serosurveillance study of pregnant women, and in Sierra Leone to assist in the Ebola outbreak.

So, to begin, Dr. Liburd.

[ Applause ]

>> Thank you Shonia and good morning everyone. Good morning to all of the -- the early risers. We really appreciate your being here at eight o'clock this morning. I know for some it was a sacrifice, but we wanted -- We were so excited about today, we just wanted
to get started early and we know that people will be leaving. It's Friday. They have flights and so forth, but I want to add my welcome to Shonia's welcome to this year's Public Health Ethics Forum that is dedicated to the thoughtful and ethical consideration of a range of health issues that affect women and girls across the lifespan. Women make up just over half of the U.S. population, and they are present in every sector. At home, they are organizing communities, raising children and grandchildren, leading foundations, national and global organizations and universities, and ensuring the implementation of sound public health policy and practice among other things. This year's forum will delve deeply into selective public health issues that in some instances disproportionately impact women. And we will explore how we can be better at improving health outcomes for women and girls from preconception to old age. Today, you will hear from women and men, just a few, who are nationally recognized for their work as scholars, as practitioners, ethicists and researchers. Our goal is to inspire lively and focused conversations about ethical issues we need to be aware of in order to deliver effective and inclusive public health programs that benefit women over the course of their entire lives. I want to take a minute of time to thank all of our partners and the planning committee. I'd like to thank Dr. Reuben Warren, Professor and Director of the National Center for Bioethics and Research and Healthcare at Tuskegee University for his commitment to the ethical practice of public health and the relationship that has been established between our respective programs. Many thanks also go to Jo Valentine and the Division of Sexually Transmitted Diseases for bringing us all together to expand the breadth of the cooperative agreement between Tuskegee University and CDC. I also want to offer congratulations on the 20th Anniversary of the Presidential Apology for the Tuskegee Syphilis Study and also to congratulate -- [Applause] And I also want to congratulate the Division of STDs on their Public Health Ethics Internship Program. I'd like to thank Dr. Drue Barrett and the Public Health Ethics Office here at CDC and Dr. Patty Tucker, Director of CDC's Office of Women's Health. And I'd like to thank and ask to stand this year's planning committee, Shonia Zollicoffer, Gwen Baker -- [Applause] -- Laura Ross, Gwen that's in the back, Dr. Joan Harrell -- [Applause] -- Benita Harris-McBride who is off celebrating the graduation of her son and Jenny Kinkaid. Where is Jenny?
Thank you.
[ Applause ]
There are also many others in the Office of Minority Health
and Health Equity in the Global Communication Center
and colleagues near and far
who have made today's forum possible.
And we extend our heartfelt gratitude to each of you.
Susan B. Anthony who was well-known suffragist
and abolitionist, once said, "Wherever women gather together,
failure is impossible."
So we begin the forum knowing
that it is impossible for us to fail.
Thank you so much for being here for those of us
who are joining us virtually.
And I look forward to the remainder of the day.
Thank you.
[ Applause ]

>> Good morning.
It gives me great pleasure to extend
to you a very warm welcome on behalf
of CDC's Office of Women's Health.
We are glad to have you here coming from near and far
to attend the 2017 Public Health Ethics Forum.
Sunday, May 14th was Mother's Day, and that's the first day
of the National Women's Health Week, which is celebrated
through May 20th through tomorrow.
Since 1999, the USC Department of Health
and Human Services Office
of Women's Health has observed National Women's Health Week.
During this time, women are encouraged
to make their health a priority and to take steps
to improve their health.
This year, during National Women's Health Week,
CDC's Office of Women's Health has coordinated the planning
and the implementation
of the Public Health Ethics Forum Optimal Health
for Her Whole Life.
In promoting and protected -- It is promoting and protecting
from birth to older adulthood the health of women and girls.
Optimal Health is as state of a complete physical, mental,
spiritual and social well-being and not just the absence
of disease or illness.
Optimal Health for Her Whole Life begins
with comprehensive prenatal care for women in all communities,
continual quality health care for all ages,
promotion of individual characteristics and behavior
or environmental conditions that reduce the effects
of stressful life events, financial literacy,
attaining higher levels of education, economic security,
ending the cycle of violence,
preparing for retirement and the list goes on.
Here in the CDC Office of Women's Health,
our goal is support and protect the health and safety of women
and girls by addressing health issues
and identifying solutions.
We hope today's forum is the beginning
of a stimulating dialogue and opportunities to exchange ideas and views and create across multicultural collaborations. And through this exchange, ethical issues are identified, and potential solutions or actions are put into practice for an impact on the well-being of women and girls across the nation. In closing, I ask that may we -- I hope that we all gain something of relevance from this day and time that we spend together at the 2017 Public Health Ethics Forum. Thank you.

>> Thank you Dr. Liburd and Dr. Tucker.

So moving right along, our next speaker is Dr. Patricia Simone. Dr. Simone is acting CDC Principle Deputy Director. Dr. Simone has served as Principle Deputy Director of the Center for Global Health and the Director of the Division of Public Health Systems and Workforce Development. There, she provided leadership in building Ministries of Health capacity internationally through the Field Epidemiology Training Program and the Sustainable Management Development Program. Dr. Simone is a retired captain of the United States Public Health Service Commission Corps. Please join me in welcoming Dr. Simone.

>> Good morning everyone.

>> Good morning.

>> I'd like to add my welcome to all of you to this forum today. I'm really happy to be here in my role as Acting Principle Deputy Director. I get the -- have the great pleasure of getting work with Dr. Liburd and her team and learn a lot more about the activities of the office. And it sort of brings me back in early 2000s, I worked in the National Center for HIV and STD Prevention before the -- the hepatitis part was added. And I got to work with the Tuskegee Program and the Minority Health Programs there. So, it's really great to be joined with this types of activities once again. I want to thank the -- all of you for being here and thank the -- the speakers that have come before me. So I have a few words for you today about CDC and this work. CDC has earned the reputation of being one of the most trusted federal agencies. And the way we're able to maintain a public's trust is by ensuring that we engage in high quality, scientifically sound and ethical public health practice, surveillance and research. Public health ethics is the process to clarify, prioritize and justify possible course of action of public health action. This process must be based on three things: Ethical principles, the values and beliefs of the stakeholders and on scientific information. While CDC excels at gathering scientific information,
gathering is not enough. We must act on this information guided by the principles of good public health practice. Dr. Liburd talked to us today a little bit already about the work of the Division of STD Prevention and the Tuskegee University. This collaboration is really important one. And in 2015, part of that collaboration was starting these ethics forum -- forum. And these forums have highlighted public health issues related to African-American health, Hispanic health data and this year, women's health across the lifespan. These four are an important way for us to come together as partners to advance health equity. CDC is committed to working with diverse populations and creating opportunities to better reach communities that may be underserved and whose voices often don't have a chance to hear. I'm also pleased to recognize the CDC's Office of Women Health in coordinating today's forum. They are shining a light on the public health issues that in many instances disproportionately impact women and girls who make up more than half of the nation's population. We already have excellent examples of this important work and I'd like to mention two of those: First, heart disease. Heart disease kills one in five US women. American -- It's the American women's leading cause of death, and yet is often thought of as a man's disease. CDC's Wise Woman Program, not just -- aims not just to help women understand their risk of heart disease, but provides services to promote heart healthy lifestyles. It targets low income, under-insured and uninsured women, age 40 to 64 years. It provides heart disease and stroke risk factors screenings and services that promote healthy behaviors. And the currently consists of 21 programs in 19 states and two tribal organizations and is administered through CDC's Division of Heart Disease and Stroke Prevention. Another example is gynecological cancer. Each year 89,000 US women are diagnosed with gynecological cancer. A teacher named Johanna Silver-Gordon died in 2000 of ovarian cancer at age 58. She had all the symptoms but did not recognize them for what they were. The Gynecological Cancer and Education Awareness Act is named Johanna's Law in her honor. To support Johanna's Law, the CDC in collaboration with the HHS Office of Women's Health developed the campaign Inside Knowledge -- Get the Facts about Gynecologic Cancer. This educates women and healthcare providers about the signs, symptoms, risk factors and prevention strategies related to cervical, ovarian, uterine, vaginal and vulvar cancers. And it encourages women to pay attention to their bodies
and know what is normal for them
so that they may recognize any persistent symptoms
and seek appropriate and timely care.
Programs like these are saving the lives of our mother,
our daughters and our sisters.
We are hopeful that today's Public Health Ethics Forum will
result in the greater awareness
of the ethical challenges associated with promoting
and protecting women's health, the formation
of new relationships among persons attending the forum
and a greater knowledge to inform all of our work
to improve the health of women and girls.
On behalf of the Acting Director of CDC, Dr. Anne Schuchat
and the senior leadership of CDC, we want to thank Dr. Warren
and his colleagues the National Center for Bioethics
and Research and Healthcare at Tuskegee University,
all of our guest speakers and facilitators
and subject matter experts,
the participating National Centers Institutes and Offices
and all of you for taking time away from your other commitments
to be part of this year's forum.
Thank you very much.

>> Thank you Dr. Simone.
So next, we have very lively speaker for you.
I'm very excited to introduce, Dr. Reuben Warren.
Dr. Warren is Professor and Director the National Center
for Bioethics In Research and Health Care
at Tuskegee University, as well as the Adjunct Professor
of Public Health, Medicine and Ethics & Director
of the Institute for Faith-Health Leadership
at the Interdenominational Theological Center here
in Atlanta, Georgia.
Prior to this, Dr. Warren served as Associate Director
for Minority Health here at the Centers
for Disease Control and Prevention.
He also served as the Associate Director for Urban Affairs,
as well as the Associate Director
for Environmental Justice at the Agency for Toxic Substances
and Disease Registry here at CDC.
His extensive public health experience at community, state,
local national and international levels range from clinical
and research work at Lagos University Teaching Hospital
in Lagos, Nigeria to heading the Public Health Dentistry Program
at the Mississippi State Department of Health.
Please join me in welcoming Dr. Warren.

>> Good morning.
>> A couple of don't do's.
Don't stop by Starbucks and get tea or coffee,
because you may spill it on your coat, and you won't be able
to wear it when you introduce our speaker.

I'm one of the few men that has the opportunity to speak
with you today, and I am so very, very pleased
and proud, one of the few men.
I'm on the planning committee that worked
to make this day possible.
And our first meeting about when we decided to do women's health,
I said very clearly, "I will argue my point,
but y'all make the decision."
And in most instances, I argued my point,
and they made the decision.
It was different than my point.
It helped me to learn that I have a lens,
but that lens is limited.
So I want you to know, your limited lens as well.
It may be around race and ethnicity.
It may be around gender and sex.
It may be around income.
And as I've learned being in Tuskegee,
it may be around geographical locale.
I grew up in inner city South Central Los Angeles,
urban America.
Tuskegee is not urban America.
I've learned a lot from being in Tuskegee.
This forum is critically important from my perspective
because it does a couple of things.
It expands and continues an authentic, ethical relationship
that has evolved into a true and authentic partnership.
And there is difference, and I'm intentional about using the word
"ethics" because that's the basis of why we're here today.
And it simply means doing not the right thing only,
not doing things right, as science drives that agenda,
but doing those things through the --
the lens of those who see it differently than you.
And understand those who have the most to lose have the most
to gain, and we ought to listen carefully
to what they have to say.
This forum started in 2015 as you've heard
because we reflected on 100 years since the death
of Booker T. Washington, the Founding Principal and President
of Tuskegee University, then Tuskegee Institute.
Booker T. Washington had a lens that was not an unusual lens.
It was one that looked at the whole picture at all of us
and focused on those in greatest need at that time.
And that sounds like public health to me.
He found through the work of some of his colleagues,
Monroe Work, a statistician in particular that the health
of black people was terribly,
terribly different than that of others.
And that difference was bad, very bad.
He found that the causes -- the preventable causes of death
for African-Americans were preventable, cost a lot of money
and cost a lot of lives.
So he established in 1915 Negro Health Week.
And what many didn't know, and we reminded them in 2015
that that evolved into Minority Health Month,
National Minority Health Month.
So when you think you're starting something new, stop,
look back so that you can look forward.
Negro Health Week is now Minority Health Month.
Thank you BTW.

The lens -- the lens of ethics has many spheres. And as many of came through looking at understanding and trying to adhere to bioethics, a very, very important paradigm evolved out of ethics, evolved out of philosophy some would say. A little bit of argue evolved out of theology. But you know, we won't argue that point. Where are we today? Public Health Ethics, a different kind of lens, one that we all think we know about because we all think we do the right thing. But it is a basis for how we should act in public health, public health ethics, here and now. Not only the intention to do good, but doing good in and of itself. Lowly, honoring and respecting autonomy but seriously engaging community, not only in justice, but in social justice. And in my view, social justice and public health are one in the same. Doing things right, the importance of science. Doing the right things, the importance of ethics. Doing the right thing for all of us is the charge of public health ethics. So we're going to move on today and understanding that we all are vulnerable. Every last one of us has a vulnerability, rather you know it or not. But some of us are more vulnerable than others. I would argue those are those susceptible populations. Those who are most vulnerable are those who we should spend our greatest resource and most attention to. Know your vulnerability and look around and you'll find somebody else with a different vulnerability. Help them and in fact, they will help you. We're in this together whether we like it or not. So when you win, I win. And quite frankly, when you lose, I lose. We're in this together. This forum particularly looks at women and their whole life, girls in their whole life. And every time I listen to my granddaughter, I learn something about women in their whole life. This is an exciting day and I'm so very, very pleased to be here and to see that you're here. Thank you for being here, and we will have a good day. Thank you. [ Applause ]

I would like to introduce, no, present a friend and colleague.

Because if you know anything about women's health, no matter how little you might know,
to introduce our keynote speaker this morning to you, would be an insult to you and more importantly to her. So I want you to take a moment this morning and listen.

I've been in school for a long time, long, long time. I'm a slow learner, so I stayed there a long time. And I didn't learn much about listening. I learned a lot about talking, not listening. So I want you to listen this morning, because in 1970, early 70s, while in Boston, I was talking, teaching and talking. And somebody told me to listen. As I did, I heard the name, Vivian Pinn, this physician at Tufts, that was finely motivating, inspiring, and guiding students, mostly medical students, mostly black students, but others in Boston. And you know in Boston, if you think you have something going, you take it to Boston.

So I listened, heard the name Vivian Pinn and how wonderfully she was doing with students. And when I joined CDC in the, like, late 80s/90s, I met some of those students were here running CDC because they listened. And Boston I listened and heard the name, Vivian Pinn. Years later, and I wandered around Harvard University, and I heard the name again, Vivian Pinn because I was listening. I went there to talk but I had to listen, and heard the name Vivian Pinn chairing the Department of Pathology, chairing the Department of Pathology, Board Certified Pathologist. I was listening and heard wonderful things about leadership in it around Howard University School of Medicine. I was listening. I want you to listen this morning. And then I, as you heard, I worked a while here at CDC and, we were trying to work with all the federal agencies and all the -- everybody else who thought they had something to contribute.

And I heard the word about the need for office of Women's Health. Heard it first here at CDC and my response because I was working minority health say, when women's health and minority health is different, so don't ask me to do it. I -- I don't know how to do it. So I asked not to do it, and then it became an Office of Women's Health. And then as I listening going through the agencies, I heard about an office or research on women's health at NIH. I said, "Now who would have the courage and the nerve to do that?"
And as I listened, I heard the name again.
You know what name that was?
Vivian Pinn.
So, everywhere I went and listened on strategies
to improve the health of those most vulnerable,
the susceptible and I listened.
I heard the name Vivian Pinn.
So when I decided to go down in the country, Tuskegee, I said,
no, I won't hear that name.

But then I say well I'm going to introduce Dr. Pinn to Tuskegee,
and I was embarrassed.
Well she said, well, if I come, I need to stop by the graveyard
to give my respects to some of my kinfolk not in the country,
the name again, Vivian Pinn.
So I want you to be real intentional this morning
about listening, not talking, but listening.
And I'm sure you'll hear something you haven't heard
before and much that you have heard before
if you listen to Dr. Vivian Pinn.
Let's welcome her to the stage.

>> Thank you, alright.
When I -- she invited me to come into government,
thinking about giving up a tenured full professorship
and a department chair in Academic Medicine to go
to government, I said, "No thank you Dr. Healey because I
like to say what I think and I don't think I'll last
in government that way."
I literally, literally said that to her.
And her response was she does -- she did too.
Why don't I come and try it?
So in fact, that was how I started NIH.
So, I'm pleased to be here and pleased to be able
to with what time I haven't lost already screwing
up this presentation.

But, to be able to talk about the topic
which is Optimal Health for Her Whole Life,
which to me is really referring to lifespan issues.
And I often think when we talk about women's health,
the label we gave, and over the years, really thought --
we really misnamed this because we really should've called it
The Health of Girls and Women to really reflect
that lifespan issue instead of just women's health.
But that's alright, we'll make up for that as we talk
about the continuum of health.
And this is very timely because it is National Women's
Health Week.

So from the standpoint of I know the perspective
of the bioethics Center, and for those of you in the room looking
in the terminology and relative to ethics, justice
and inclusivity that National Women's Health Week is a
wonderful time right on topic to look at the issues related
to women's health or the health of girls and women.
Now, I can say and I'm sure there are many
in this room who've been involved
in women's health for many years.
And Marsha, I'm going to call on you in a minute.
But I'll get to you in a little bit.
That's doctor -- that's not doctor, but Marsha Henderson
who is the Director of the Office of Women's Health
at the Food and Drug Administration, before that,
held many positions and has been with that office for many years
and has really been a wonderful colleague.
I probably now don't get her in trouble
since I've been retired for six years.
So, she's on her own and she can behave
without me steering her on, but has been a great champion.
If you don't know Marsha, stand up Marsha
so they will know who you are.
[ Applause ]
But many in this room I know have --
and we're well aware that how we define and what we think
about women's health, how women's health or the health
of girls and women really has changed since the late 1980s
and especially since about 1990.
And that came about because of advocacy combined
with scientific legislative public policy
and human rights considerations.
And it really is important to reflect on that because it shows
that when you have concerns,
that actually it was grassroots efforts that led
to eventually a change in public law for this country.
And so we can bring about change if one is dedicated enough
to what we are trying or one is concerned about.
So what was the historical view?
We talk a lot about the traditional view
of women's health.
And actually I -- because I didn't want to have 1500 slides,
didn't put them in, but there are textbooks
and there are many documents from the 80s and 90s.
And I go back and look.
I finished medical school, I hate to say it,
but I finished medical school in the 60s.
And looking at the textbooks that we used at that time,
and women's health was defined really in terms
of reproductive health.
Women's well-being was defined in terms of her sexuality.
Women's health was really considered
to be the reproductive system during the reproductive years.
If you ask what was men's health,
it was the total body system everything from head
to toe, all of the systems.
You ask, what was women's health?
They send you to OB/GYN because it had to do
with reproductive health with pregnancy.
Almost nothing related to women's health after menopause.
It was as though once you hit menopause,
reproductive years are over, you just sat in a rocking chair
on the front porch and you rocked and that was it
until you passed away, as opposed to looking
at healthy aging, etcetera.
So, doctor -- I think Marianne -- many people have claimed it,
but as I look back, I think it was Marianne Legato, who first gave the label, The Bikini View of Women's Health to that idea.
Well, we've made some changes, and one of the first things that we had to do at NIH when we began to study women's health and to really look at it from the standpoint of research, which very important is two things: One, to recognize that women are not the same as men because this whole concept of attention to women's health, really came about because of the concern to whether not standards of medical practice were being based on information that came from the study of women or where the studies of health issues in men aside from reproductive issues done in men, were being applied to women as though women were just little men. And obviously that's given rise to the whole field of sex and gender-based medicine and policy if you will -- but also recognizing that women's health didn't begin at puberty and end at menopause, but that it really encompasses the entire lifespan. And so we had two things to do -- One, to bring up the concept of comparing women with men and secondly, to look at the expanded concepts of women's health and not just from birth to grave, which is what some like to refer to. But as we talked about sex and gender differences and obviously based upon many things I had been involved in and the fact that I was heading this office, we could not just look at women in terms of the fact that women are not just like men. But the fact also that not all women are the same, that there are differences between different populations of women, and it may not have been popular in 1991, but one of the first things our office did was to declare that as we look at women's health, there would be two aspects: One, to look for differences between males and females and secondly to look for those factors that contribute to differences among different populations of women or different populations of men, which to me is a way to -- to explain why there are health inequalities, why there are health disparities. And looking at those factors across the lifespan if you will, not just in terms of health status, but health outcomes. How do we respond differently in response it interventions and responses to the environment in which we live, which we were born, in which we grow up? How do we respond different to treatments? And that really -- this slide really kind of summarizes the essence of what I really worked for and how I constructed programs during the 20 plus years I was at the Office of Research and Women's Health at NIH. If you didn't know, Dr. Warren didn't tell you, I'm supposed to retire in two months as of six years, and you would not know it from my schedule. But anyway, I am supposed to retire and I have flunked retirement, but that's another story. But looking at health disparities
and health inequalities, and I must say that CDC has a lot of wonderful information really coming out of the Office of Minority Health and the other parts of CDC with good literature and good explanation about health disparities and health inequalities, which I often quote when I'm speaking about health disparities.

But we all know what health disparities are. But I -- I had this this slide that I often use, but I added the section, Gender Equity is a Social Determinant of Health, because as we talk about those determined, those factors that contribute to health and that contribute to health disparities, I just -- On, what was it? Wednesday, two days ago, I can't keep up with the NIH, where they have a lectureship for women's health. And it was interesting because one of the speakers made a big point of looking at social determinants of health and emphasizing that gender equity -- gender equity is a social determinant of health. And I think I've been implying that, but I like the way she emphasizes, so I added that to my slide to make that point because we know that the Center for Bioethics is focused on and wants us to consider social justice and -- and -- and -- and social justice, and to me, that brings that forward.

And as we look at what's happening in terms of looking at different populations of women, we know that there are differences in health status/health outcomes, access to care, and that term which we need to now reframe in the current sociopolitical environment, really differences in that if we're going to make a difference and overcome these differences, we need to know what we need to overcome. Anecdotes don't work.

To me, that is the value of research that we have the evidence so that we know what we need to tackle, what are leading to? What is resulting in these health disparities at different points of the lives of women and different populations of women. So, when I went to NIH and many asked, "Why did you leave Academic Medicine to go to NIH and become a federocrat, if you will?"

It was because having been out there like with Dr. Warren and many venues we've been in, knowing we were trying to make a difference in what was happening for health of our people and our communities, as well as people in general, knowing that anecdotes were not working, that we really need to have the information based on the fact that there now is going to be an office that would be focusing specifically on getting the data and -- and what we have as the evidence-based system of medicine.
And in order to change standards of health practice, in order to change what is taught in health profession schools in order to change what women and their families are told about preserving their health, we don't need stories that are carried over. We need evidence. We need information. So research is important, and having that information from research, then having those -- that information incorporated into healthcare, as well as into public policy can then help us to change and require some changes and standards of healthcare delivery, as well as know what to inform women and men and their families about what they can do to preserve their own health.

So, I mention this and I'm not giving a lecture on inclusion, but it's important because this is what came about. And actually, I have to give a lot of credit to Dr. Warren because the center at Tuskegee has really focused so much over the years and continues to on the importance of inclusion and clinical research of women and minorities in -- in generating results and actually has had several number of symposia dealing on -- dealing on the issues of inclusion, and I think -- Well, even, I know that you're working on a project on that now, but I wanted to just emphasize this.

If you think about it, actually the actual change came about out of the Women's Health Movement, because it was the Women's Health Movement that actually went to Congress and said, NIH is not including women in clinical studies. We need to make sure they're going to do that, and a policy for the inclusion of women was developed. But then there was some who said, well what about minorities, which was the terminology used then. And so, then the NIH guide said, well let's add the word "urging."

So after inclusion, then -- then -- then there was a -- Language was added that said we encouraged the inclusion of minorities in clinical research at the NIH. And then the general accounting office at the request of Congress, looked to see whether NIH was following these guidelines, and were women and minorities being included. Focus was primarily on women, but it also looked at whether or not women were being included, and it was actually NHLBI, the National Heart, Lung and Blood Institute that seemed to be doing the best at that time in 1990 in ensuring that women -- that members of minority communities were being studied. But when that report came out saying NIH was not doing it, it was a press conference held on NIH's campus to lambast NIH for not making sure that women were included in clinical studies that led to the then Director/Acting Director of NIH to announce we're setting up an office to make sure this happens.
And that was what the genesis was for the Office of Research on Women's Health. It really was established to respond to concerns about the inclusion of women. You can't separate women and minorities. And although there was an office of minority health programs at that time, you can't separate and have two different sets of data. So actually we ended up doing -- looking at most of the issues related to -- to inclusion of both women and minorities. And as I think you should know in 1993 what had been public policy became a matter of public law, and as far as I know, we're the only country in the world that has a public law that requires in federally funded research that women and minorities be included in clinical studies. So that is sort of the genesis of what came about. And actually in presenting this, when the law was passed, it really just strengthened the policies NIH had. This was in the NIH Revitalization Act. FDA has since had language directing it to -- to look at reporting. Remember FDA does not fund research. It is regulatory body so it doesn't fund research. At NIH, we could say, you won't get the funds to do your research if you don't meet our policies and requirements, while FDA has to evaluate research that's done independently and has brought to it. So it's a little bit different. But we were so proud that we were able to show that we were beginning to include women and minorities in clinical studies. And then I begin to get letters from members of Congress, mostly male members saying, "NIH is discriminating against men because all data is looking at women and minorities in clinical studies." So, I learned that when I talked about this, I had to automatically just cover myself by saying that we assume, and the basic assumption is that men are being included in clinical studies, and the purpose of our efforts are to make sure also that women and members of minority groups are also included in these policies, the purpose being really to get back to the concept of ethics and justice to make sure that results of research are applicable to all segments of the population. Remember prior to this effort to move into inclusion in one of the major areas that we've all had to deal with is that for years, women were not included. And one of the reasons -- one of many reasons, but the major reason used to justify that was that women were vulnerable. It was going to hurt them to be and then there were going to be problems. And the same with the reference to the --
the PHS Study at Tuskegee
that maybe we shouldn't have African-Americans
in clinical studies because we should be protecting them.
We -- we should not be using prisoners because --
Five minutes and I'm through?
Oh wow. Well, maybe I should just stop now.
Let me see here.
In any case, let me see what I can do
because I'm just getting into this.
But it -- it's a matter of looking at inclusion.
It is a matter of ethics and justice.
Alright, seven minutes.
I'll see what I can do.
And so, we look at and think about these principles
of justice inequity that they really need to be considered
in the multiplicity of factors that contribute to
or prevent good health and wellness in girls and women
across the life continuum.
And being able to not just have access to healthcare,
which is what we've been referring to and always referred
to that we get the results to research, we know what state
of the art or art of healthcare is, and we want to make sure
that women and minorities have access to that healthcare.
But in the current political environment, we're learning
that we can no longer just talk about access to healthcare
because we're learning that that word can be used differently.
Having access and actually being able to take advantage
of that access is a new way of looking at that terminology.
So we all are going to have to think differently
at how we express that.
And so, out of this, I've now moved into a new terminology,
and I think this is going probably be at the basis of most
of my talks about health and healthcare now
that we really have to think
about the sociopolitical aspects.
Now, I am retired from government,
but I still have a government title,
and I'm in a government building.
I'm not being political, but if we want to think
about contributors to healthcare,
we have to think and health status.
We have to think about those sociopolitical aspects.
And if you're familiar with that report that came
out about differences in health and -- and --
and mortality in different counties across the US,
I just heard a presentation on Wednesday looking at that
and that one of the major contributors
to differences are state policies.
And as we look at the discussion now about --
about what's happening in terms of healthcare
and perhaps a new healthcare bill
and whether the states will be controlling our
national standards.
We need to be concerned about those sociopolitical aspects.
Alright, let me see what I can do in three minutes even
with the southern accent, Reuben,
let me see what I can get through here very quickly.
We've always talked about the many contributors to differences in health status.
And I think women's health was one of first areas to go beyond just the biological factors that contribute to the women's health.
You cannot look at women's health and think about women. Perhaps this should've been true for men, but at least we did this for women, and hopefully the men's health area learn from this too that we can't just think of it in terms of genes and biology and environment, but we need to think of all of those other factors.
And we really begin looking at social determinants of health. This is not my diagram, but it's a wonderful diagram that -- that I've adapted and used from -- from that article by Dahlgren and Whitehead.
But if you think about it, we really started looking at social determinants of health before there was an office of bio-behavior and social science research, before there was emphasis on that.
And so when we look at factors related to the health of women and girls across the lifespan, we do focus on and we have to continue to focus on, and especially in today's environment behavioral and social are societal factors, as well as looking at race and culture, how women relate to their bodies, environmental exposures.
You know, not just looking at endocrine disruptors in the soil, but also looking at things like -- like access to toxic waste that -- that there may be in an area or where one lives with how far you are if you're in a rural areas from having a -- having access to a physician or a nurse or a clinic, and also looking at that access to medical -- to medical practice or I should say healthcare practice, and of course looking at life course.
We -- we've seen many different variations or divisions of life or the periods of life, of course the life span. And mostly, it boils down to prenatal infancy and childhood years that have less years, reproductive middle years, pregnancy years, menopausal transition years and the elderly frail, elderly and healthy aging years to sort of separate those who are healthy elderly and those who are elderly but frail because there's sort of a difference there in terms of -- of looking at health and health divisions.
But the important point is that it's really a continuum of life. It's not a -- it's not that you jump from one to the next. And you know it's like people and you see references often referring to women under 50 and over 50, we know that age 50 is arbitrary because it's used to sort of suggest premenopausal and postmenopausal, assuming that age 50 is the stand-in or the surrogate for menopause, and yet we know some women undergo menopause at a much earlier age.
Some women undergo menopause at a much later age. So you can't assume that once you're 51,
you're automatically fitting in all the data related to women at age 50 and over or under. So we really need to think of our life course as a continuum, and that's what makes the lifespan or life course important. And -- and actually, when we think about it, and with that in mind, we really and one of the most important things to come out of not just women's health research, but I think out of science are those concepts to help us recognize that there are contributing factors not just from birth to death, but actually from pre-birth, meaning the entry uterine environment that can affect our health as we become adults and as we age. And so we really need to think about that comprehensive continuum from the entry uterine environment. I like this slide which came out of our strategic plan that we did that really is sort of based on the Barker Theory that is that if you look at conditions or statuses, even things like substance abuse occurring in -- in adult years or later years, that often it can be tracked back to influences in the pre -- in the in utero time. And so that Barker Theory, we actually spent a lot of time funding research in that -- don't hear as much about it, but it's beginning to come about again. But it really comes down to the idea of looking at the importance of the in utero environment for healthy babies and for healthy adults really with that spectrum, which is why I have a great time not understanding the objections for providing maternal care, but that's another issue, but actually thinking that if you provide, and whether you're male or female and you're helping to support maternity care, maternal healthcare that you're actually looking out for both men and women in their later years because of the effects a lack of prenatal care can have on the health of the fetus and therefore the health of who's going to be the adult male or adult female 30, 40, 50 years later. That is important. But -- And so we can look at the health factors, keeping in mind it's a continuum for prenatia infanty and childhood years really looking, mostly focusing on the implications of the in utero environment and prenatal exposures. We don't see a lot of sex differences and a lot of differences other than -- than -- than -- than low birth weight babies and mortality and maternal mortality in those early years. But getting into adolescent years, which is where bad behavior seem to begin to form. You have to worry about sexually -- sexual maturity and -- and -- and what's happening with -- with -- with STDS and handling the sexuality, looking at eating disorders, obesity,
as it comes are the other extreme eating disorders.
Yes, teens are beginning
to experience intimate partner valance even
in the adolescent years.
We're seeing issues related to drugs of choice, but I'll get
to that again in a few minutes, but looking at the teenagers
with their parent's prescriptions out of their --
their bathrooms for substance abuse
because it's "a fun thing to do."
But we know that seven out of ten deaths for kids in --
in this age group are related to unintentional deaths
like motor vehicle accidents, homicide and suicide.
So these are things that need to be considered in that age group
as we trans -- but then also, how good are we
at delivering healthcare?
Do teenagers -- do adolescents, do they go to the pediatrician?
Do they go to the gynecologist?
Do they go to the general internist?
Do they go to the family practitioner?
Or do they go to their friend next door and ask, what do I do,
and go to their buddies in the --
in the local gang or local -- local group?
So we really need to give more attention to healthcare,
health direction and health information, because we do know
that ten -- teens can carry out some wonderful ideas in work
and help improve the health of their parents
when they're in on it.
And then looking at reproductive in middle years,
we talk about going beyond the reproductive system,
but there is so much more we need to know
about the reproductive system, so we can't forget that.
They're reproductive health issues.
And again, it is important to have healthy pregnancies,
full-term babies, and that continues to be important,
in addition to fertility issues, as well as --
as fertility issues and -- and reproductive health and things
like fibroids and endometriosis.
But then really looking at obesity,
and we know how obesity affects.
We look a healthy behaviors.
Intimate partner valance really becomes an issue here.
Cardiovascular disease and you've already --
So I'm not doing a list of all the diseases,
because I'd spend all day doing that, and you're familiar
with them, but just pointing out so many issues
that are a major concern during this particular part
of the lifespan continuum,
and course cancers especially this age,
breast and cervical and melanoma.
Now with the idea and it seems
that every place I've been recently
and I've been too many places recently,
but almost every place I've been,
I was in Boston just a few days ago, and then again this week
at several meetings, there have been discussions
about overdose -- opioid abuse
and I know you have discussion session coming up.
But you heard my background is pathology, so I recently had visited the -- the DC morgue and the --
the medical -- the chief medical exam, there's a great young man, Roger Mitchell who is now in charge of that office, but he was telling me about the increase
that they're seeing right in DC.
So I just looked, wanted to see how that -- that --
that how the data there really would look when put in terms
of national data, which you'll be hearing about.
But it's interesting because you can see that the major increase
in drug use and drug overdose use is among age 50 to 59,
and so not in the teenage, but the later years.
Actually and women constitute only about 25 percent in DC
of those who die from drug overdoses, but it --
it's interesting to see -- and it's --
it's nice to see that women went down a little bit last year.
But look at the -- look at the variations
by race and ethnicity.
This is the kind of data want to see.
And just look at -- look at blacks for example.
Now, the red line for 2017, this year is only five months
on the way so we don't have much data yet.
We hope it won't catch up, but look at the difference
between 2014 and 2016 and the number of over --
opioid deaths, and of course they're mainly opioids fentanyl,
etcetera and derivatives, etcetera.
So while the --
while these fatal overdoses are more common for males
than females, we still have the issues of women
who about 25 percent are women, but then beyond that,
when we lose the young men or the older men,
the impact on the women of the family in caregiving
and taking care of the family and the impacts
of women are affected.
Menopausal transition -- I -- I could --
If I could take off my jacket and show you my back,
I could show you lots of scars related to the fact
that I was the co-director of the Women's Health Initiative
which you may or may not recall was the study that looked at --
It's a broad study and CDC was actually very involved
in the public -- in -- in the public health studies of that.
But the major thing the Women's Health Initiative is known
for was of the stopping of the study early with recommendations
that menopausal hormone therapy should not be used
for prevention of cardiovascular disease or prevention
of other diseases and that there were more risks than benefits.
And my back still itches from the attacks I got from that.
Well, that was 2002, and it's continued on.
I just want to show you that for the menopause area,
the menopausal transition to come --
the major concerns continued to be
around the use of hormone therapy.
And I want to show you that the preventative services task force
just came out this week with putting
out again recommendations which essentially say what
in fact Marsha Henderson can tell you is the FDA actually has
the -- gives the -- the FDA has never approved the use
of hormone therapy in menopause for the prevention of chronic diseases, although that's what most physicians used it for and what most women thought they were taking it for, prevention of chronic diseases and to keep them young and sexy, which is what we were sold on -- sold through our traditional -- Don't let me get started on that.

In any case, I want you to know that this is again coming up. This is just this week, but actually what they're recommending is something that is actually Marsha and her office are really responsible for the education of women about this topic. So I just wanted to show you that.

And then looking at elderly and frail elderly years --
And I was watching the clock.
I started at five minutes after would --
so I think I have another five minutes.
Is that okay?
Alright.

>> Alright.
>> Thank you, because you really called me up for five minutes and it was 15 minutes, but anyway.
Sorry, I'm watching.
But looking at the elderly and frail elderly years, that's when we get into issues like osteoporosis, as well as cancers, again breast.
We know the greatest risk for getting breast cancer is being a woman and getting older. And then looking at the fact that the new data shows that opioid and drug deaths are increasing in older years.
But the major we can summarize all that by saying that when one gets older, especially for women, but it's true for men too, but especially for women, we live longer, but we're more apt to have complex chronic diseases.
We don't have just one condition.
We often have an interaction of chronic diseases and that can be a major issue for healthcare.
So when we think about interventions for health disparities for women of color or women in general for midlife to beyond, we want to lessen disparity.
We want to prolong life.
We want to preserve mental acuity.
We want to prevent functional, physical decline.
We want to be able to get around, be mobile, not have to go to a nursing home become of incontinence or not being able to -- to have free mobility ourselves and continued -- I shouldn't say improved, but continued good quality of life.
And I just want to mention briefly a major area, and I know that -- that it's interesting if you go to your college reunion or school reunions and you see the differences, as you age along that continuum, I remember when I went and --
And where is Rochelle who's also a Wellesley grad? I remember many years ago I went and everybody was talking about menopause because the class was getting to that stage where everybody was going through menopause.
And of course then I had all the answers I thought from the Women's Health Initiative. Then the next one, everybody was talking about dementia because so many people in the class were affected by taking care of parents or relatives with dementia, their in-laws or their own parents. And that was the discussion. I don't know what it's going to be when I go back for my 55th reunion next month, but I can imagine. But anyway, but knowing that dementia is a major problem. And we do know Alzheimer's is more common in women, not just because we live longer, but now it's been shown it really is more common women even -- even with or in spite of living longer. And so we look at attention to -- to dementia in that not just Alzheimer's but other forms of dementia how important it is, but it then raises another area because important for women's health actually looking at what have some referred to as the Sandwich Generation for those who are midlife who are taking care of older parents, as well as young, their grandkids. But then also looking at the fact that for caregivers, most are older. One in ten of caregivers in this country are 75 years or older, and then we have the women who are giving care and the women who are needing care. And what I'm often preaching and people ask how well I do. I don't do so well myself, but I hope all of you are doing better at taking care of yourselves, because we can't take care of everyone else. So now caregiving has gone from just a sociocultural concept to actually being the basis of research, being the basis of studies, being the basis of the science. What is the role of stress in health? How does stress and stress coming from caregiving, as well as other factors affect the health of women? Well, then to just sort of bring this to a close, I've looked at this sort of in terms of lifespan, but then many like to look at the health of women in terms of leading causes of death. And these are obviously from the CDC data. But heart disease, cancer, and you notice stroke used to be three but now chronic obstructive pulmonary disease has moved up to three, Alzheimer's is number four, and look at diabetes that comes down. So those are for all women. If we look at the divisions on the basis of -- of racial and race and ethnicity, we can see some variations while heart disease is the most common for all women and for white women and black women, cancer is the leading cause of death for Hispanic, Native American/Asian Pacific Islanders. But you can still see that these same conditions, whether they're one two or three, they're all important in the health of women. So we need to think about prevention. We need to think about treatment.
We need to think about education and which populations are at higher risk, and what are those contributors to higher risk?
Because if you want to eliminate disparities, you've got to know what you're tackling so that you can do -- be strategic in your planning and that is important -- important in -- in going there.
And if we look at different racial groups, while we see the top ones, these are the conditions that if you look at various groups that you could really summarize, and I'm not going to go through all of those.
And then looking at threats to help the age in caregiving, wellness, staying active, mental health which is so important and looking at sexual health, which we don't talk about that much, but how important that is, not just for young girls, not just for adolescents, but also looking at older populations.
And if some of you have heard some of the stories from nursing homes and those that run nursing homes, we know that these are issues, but that's healthy living supposedly for those who are at that stage in age.
So we need to think about all of these issues in addition to drugs and alternative medicine when we're thinking about lifespan issues.
And then we bring in the immigrant populations. We now got more immigrant women, and they bring sometimes different, not only different conditions to be concerned about, but different cultural values, different family relationships and how that affects their ability to get healthcare or to get healthcare or to participate for example in clinical studies.
And then looking at other undertreated, I'm calling them undertreated, under-health service populations like the poor or those who are in inner city urban areas or those who are in rural areas.
How do we then make sure they're getting access to health services and not just access, but actually being able to benefit from that?
We've got to make efforts to improve health communication and health literacy.
We've got to examine better -- and I know many of you are doing this, and you'll probably talk about some effective ways to disseminate health information and better use some of the new social networks that can get this kind of information out and with the focus on prevention.
So we know that preventive behaviors can reduce the risk.
And I want to just point out something that really concerns me quite a bit.
We know that from research, and I've talked about research actually affecting practice patterns, that the IOM had a committee to look at clinical preventive services for women, using the latest in research on what really can make a difference in the health
of women through preventive practices.
And out of that came as part of the ACA recommendations
for preventive services for women,
which were then based upon research,
based upon the IOM report, were then incorporated
into healthcare as part of the ACA bill.
These were going to lose if the ACA is done away with.
And my question is, what happens when we think about the lack
of maternal healthcare?
What happens when we don't have support for these kinds
of screening services?
And when we talk about -- talk about access to healthcare,
it's available, but how will it be available?
To me, this is a good example of how research has moved forward.
We know about the risk factors for heart disease.
One of the things I get concerned about is that,
and that some of them we can modify,
others are not getting the message
out with heart disease being the leading cause of death, from --
for most women, how do we get women
to understand what they can do to protect themselves?
But also we don't want to make a guilt trip for women
when they're thinking about -- And just one last example
and then I promise you I'm through, when we talk
about diabetes, and we know that there's differences
in diabetes prevalence.
And we look at gestational diabetes,
and we know that gestational diabetes occurs most often
in women, especially from women of color, and that we've learned
that what is important talk about life continuum,
that women who have developed gestational diabetes have a
greater chance of developing Type Two diabetes.
After the pregnancy, you know gestational diabetes usually
goes away and women are told to get a sixth month checkup
and the diabetes has gone away and they think they're fine.
But we've learned that actually they're more apt to later on,
maybe years later develop Type Two diabetes.
But more importantly, the children
of these gestational diabetes pregnancies are at greater risk
of future obesity and Type Two diabetes.
And that means that pediatricians need to know
that they are born of GBM -- of -- of GDM pregnancies.
And that recommendation needs to be carried forward.
To me, this is a great example of showing the continuum
of conditions and how, you know, this is the in utero environment
and how it can lead to adult disease and conditions.
And that means we need to make sure
that our healthcare system accommodates that.
Well, you know about all of these
and I just mentioned Precision Medicine, which is sort
of basing -- and everybody's doing it
because there's funding right now for Precision Medicine.
So everybody's focusing an institution
on developing Precision Medicine initiative.
But it's based on the genetic approach to the individual,
but I'm hoping in that genetic approach
to the individual we don't forget the importance of ethical
and social implications of this new approach but also looking at all of the other factors that contribute to the development, the manifestations of genetic diseases, but also the whole health of the individual.

So, how do we proceed?

There's still a major challenge to overcome some of those political biases about what constitutes women's health.

We need to continue to get the message out that while the reproductive system is important, women's health is more than just abortion and contraception, and I don't know how we get that point across more than we have.

We keep trying, but we have to recognize and make sure that our leaders and our funders understand that women's health is more than just contraception and abortion, but reproductive health is important -- that we look at some of these contributors to health and equities, that we need to be informed and make sure that women and their families are informed.

And again, here I go with my latest soapbox issue dealing with the sociopolitical aspects of healthcare policies and practices.

If we are going to have justice for all and -- and human rights preventing women's rights are human rights, that we really make -- need to make sure that biased and uninformed politics don't affect what we do.

So, efforts need to continue to provide advances that means through research and basic knowledge, prevention strategies.

We need effective information dissemination.

We need more effective cures and interventions if we're going to take care of these diseases that affect us, but always with whatever we do, keeping in mind ethical principles and common sense approaches, because it doesn't -- we can be held as smart information, but you got to have a good dose of common sense with it and how it's applied and what we do with it if we're going to bring about the kind of health equity that Dr. Warren always talks about and takes us forward with.

And I know you're going to pull me off the stage, but this is my last slide.

Thank you very much.

[ Applause ]

>> This next session is within the program is our Plenary Panel discussion. The title is Women's Health at the Intersection of Context, Inclusion, and Public Health Practice a dialogue.

So, the plenary discussion includes women representing racial and ethnic perspectives, women who live in rural areas and scholars of religion and ethics.

They will grapple with the larger question of how can we ensure an ethical practice of public health across multiple dimensions of women's lived experience? So we're very excited to hear the dialogue that's going to take place today.

Moderating our dialogue is Dr. Dazon Dixon Diallo.
She is a recognized visionary and advocate in the struggle for women's human rights and reproductive justice, and the fight against HIV/AIDS, on behalf of communities of women living in HIV—living with HIV and those at risk for HIV and STIs. Dr. Diallo is Founder and President of SisterLove, Inc, established in 1989, the first women's HIV/AIDS and Reproductive Justice Organization in the southeastern United States. Dr. Diallo is a member of the Board of Directors at the National Women's Health Network, and she is a founding member of the 30 for 30 Campaign for Women in the National HIV AIDS Strategy. She serves on the Fulton County HIV Advisory Board, and is a co-chair for the Act Now End AIDS national coalition. Diallo was recently appointed to the NIH, National Institutes of Health Office on AIDS Research Advisory Council.

She has received numerous awards and recognitions over the 32 years she has been working in HIV/AIDS, and women's health and human rights. Please, a round of applause.

[Applause]

>> Thank you.
Give me my hug.

>> For you, thank you so much for that.

>> Thank you.

>> So SisterLove is not an accidental name for the organization.

I -- As we get started, I --

I just wanted to first say thank you for this opportunity. It is a privilege, and I know, and I'm going to say this very quickly as she walks out of the door, it's been my privilege to have an opportunity to be in the room and to hear Dr. Pinn address. Because I believe that in 1983 when I was a student at Spellman College, I became the youngest, nonfamily member of the founding of the National Black Women's Health Project, which is the first ever black women's health conference held in this country at a national level on black women's health issues in 1983, founded by Byllye Avery, and Byllye had the foresight even then to make sure that Dr. Pinn was a part of that really critical and historical conversation.

I'm a proud member of the National Women's Health Network. So in a lot of ways, we have relationships with just about everybody who's on our panel today and I'm excited to hear their thoughts and ideas on some of these challenging issues around the ethical practice and public health and in women's health across the lifespan. I'm also really grateful for the question around community-based participatory research and community engagement because that is something that we struggle with a daily basis as the fact that we are also a part of the Women's Inner Agency HIV Study as the only community-based organization directly contracted
into the study as a research partner. 
And I would be remiss to say that just as a person who is
in her early 50s that I am "perimentalpausal."
I am -- I am not confused about what I just said,
and that I think that mental-pause and --
and that I think that mental pause is probably more
of an accurate description of this experience,
and so I ask early on forgiveness
if I get a little few lapses as I go
through meeting our new folks this morning.
So we're just going to start out, and I'm going
to take my seat in a moment.
But this really is a dialogue and discussion.
So it is sort of the same way I run my radio show.
It's a kitchen table conversation.
We just left the kitchen table down there
on the -- on the floor.
And we're going to start with folks giving us just a couple
of minutes about yourself and maybe inside those couple
of minutes, a reflection or two about what we've talked
about so far this morning
or what we're having in our conversation.
So I'm going to start immediately with my left just
to give you a sense of who's in the room.
We have Professor Dr. Rosetta Ross,
who is at Spellman College
and she'll tell you a little bit more about herself.
And then we have -- Is that Maria sitting right next -- Yes.
And then we have Maria Lourdes Reyes who was with
the U.S. and Border Programs Project Concern International.
She's the Director of that -- of those programs.
And then we have Judy Monroe, President and CEO
of the CDC Foundation.
And at the end, we have Kathy Yep,
Professor at Pitzer College of the Claremont Colleges.
So, can we just start with our first discussion question
and then role?
Alright. So, I'm going to just start with our number one,
according to the 2017 Proclamation
for National Women's Health Net --
Health Week, Cindy would love it
if I mistakenly said National Women's Health Network,
women are more likely to be the primary caregivers
for their families, caring for their children, spouses,
partners, parents, caregiving especially
when a family member falls ill,
and honestly sometimes our employers, our coworkers,
our church members, our friends --
I tell you my aunt who is a retired Family Planning Nurse
ran five family planning clinics for the Fulton County Department
of Health and Wellness -- been retired almost 20 years
and is still the nurse to the family, the community,
the church, the neighborhood and anybody else who happens
to learn that she's a nurse and needs care.
In doing so, many women tend
to put their own health needs on the backburner.
So what are some of the primary challenges
that impact our ability to address this behavioral tendency and other factors that negatively impact the health of women and girls across the United States? So prioritizing our lives begins our conversation. And anyone who is ready to jump in, I guess we would start right here with Rosetta introducing yourself. And then we'll go down the line and come to the question in discussion.

>> So again, my name is Rosetta Ross and I teach Religious Studies at Spellman College. Prior to teaching at Spellman, I did teach at seminaries. My research focuses on religion and women's social justice activism and particularly do I focus on women in the Civil Rights Movement -- African-American women in the Civil Rights Movement. Recently, I have been working with African and African diaspora women on ways that religion interacts with the quality of life of women and girls across the -- the lifespan and there are both positive and negative factors as you can imagine. So we're going to introduce ourselves and then respond.

>> Yes.

>> Okay.

>> Thank you. My name is Maria Lourdes-Reyes, and I am the Director for the United States and Border Programs for Project Concern International, a nonprofit organization. We are in 15 countries, Asia, Americas and then the -- the Africa. So my work -- I am a pathologist by training and practice, and like Dr. Pinn, but found myself truly looking at the communities that we serve. I was past President for the American Cancer Society for the state of California, and was very involved in the cancer world. I also worked with the NIH, UC Irvine, being the research liaison for the communities on Pacific Islander Cancer Control in Guam, Samoa, the United States, Tonga. But I found myself moving onto public health as a pathologist, really looking at the communities. So prior to going back to a Master's in Public Health, I -- I went through the business school really understand what does that mean? Why -- why do we have many programs and yet people don't come? And so really looking at where are the communities? What do we need to do that really needs to be from the bottom up and not our usual top down approach? So having moved onto public health then, I found myself at the beginning of life. Can you imagine? I'm a pathologist to really looking at the end of life. And then the program came about where I became the Director
for a Healthy Start Program, a pregnancy program for the -- for HRSA, and so the beginning of life.
And I said, wow, okay, public health is public health. Medicine is medicine. I can do this. And so I really started with that and moved from that program to now a highest funded level with HRSA looking at mentoring other states in Arizona, Texas, New Mexico, California, really looking at what are those disparities in -- in pregnancy. But then of course I'm a pathologist, so it's a life course -- a lifespan.
And then have many programs now with chronic disease prevention. And just recently, working now with the Alzheimer's Association and Hospice. So, I feel like I -- I -- I feel like I have really looked at the entire spectrum of life, and -- and then all of the above. And truly, my personal mission statement which is what I want to share is that I am dedicated to the realization of human potential through servant leadership. And so as a servant leader, I am really at the bottom serving the community. And that is how I wanted to live the rest of my life. We're not talking about age, because I think I'm the oldest on this panel, but anyhow as public servant leader. So thank you. >> Thank you. >> So I'm Judy Monroe. I love that mission statement by the way. So I started my career as family physician with the intent of practicing in an underserved community and had a National Service Corps Commitment through HRSA that took me to Appalachia and practiced in -- in rural America, where it really hit me hard, the issues facing women and rural women. And from there, my husband actually led me into academia. We went to Indiana University. I joined the faculty there. From there, went to St. Vincent Hospital, part of Ascension Health to direct the residency program in Family Medicine, where I thought that was -- would be what I would do in my career and did a lot of women's health through the residency program and a lot of teaching, but then was called to be the State Health Officer in Indiana, and that was my journey in from Medicine to Public Health and I became a State Health Officer in 2005. And after five years of serving as State Health Officer and loving public health, then I was called here to CDC and became Deputy Director under Dr. Tom Frieden, and -- and reported to him for six years. And now I'm with the -- And I established -- We established the Office of State Tribal, Local and Territorial Support where I had an opportunity to work with all the health departments and communities across the nation. And now I'm with the CDC Foundation,
pleased to be in philanthropy.

>> Hi, good morning.

I want to thank the offices of Women's Health and Minority Health Equity and the National Center for Bioethics and Healthcare for this interdisciplinary conversation, grassroots and grasstosps.

I think it's really innovative in that way and it's an honor to be on the panel with you.

So I am Kathy Yep.

And my pronouns are she, her, hers.

I'm a cisgender Professor of Ethnic Studies, and I'm based in Claremont Colleges, mostly an Associate Dean of Faculty looking at faculty development, as well as diversity equity and inclusion. And think my offering for today is thinking about the framings of a research.

So in pivoting away from just exclusion to inclusion, but to thinking about the paradigmatic and positionalities and how do we ask questions, who's in the room? Who's not in the room?

I'm a fourth generation Chinese-American. My family is all San Francisco Chinatown, and the first generation college student, first generation faculty and now administrator. And I think in terms of what I hope to bring to this conversation is ways that women and under-resourced populations have different forms of knowledges that can inform our decisions on a policy level and healthcare level.

>> Thank you.

I'm already fascinated, how about you?

>> Yeah.

>> Yes.

>> So let's come back to the question, right. What are the primary challenges that impact our ability to address the specific behavioral tendency around women caring for so many others before we care for ourselves and some of the other factors that negatively impact the health of women and girls across this country?

Who wants to jump in with what your first reaction to that question was even when you first got it in your email? What did you go, humph?

>> So -- so -- go ahead.

>> Well, I'm -- I'm going to jump in because this -- this question hit hard for me. A year ago, Mother's Day weekend, my husband and I attended the wedding of a really great friend of ours, a pediatrician we'd known through the years that was practicing, actively practicing pediatrics in rural North Carolina.

We attended her son's wedding and it was a wonderful weekend, just fascinating. Now this individual -- this friend of ours always took care
of everybody before herself, her patients, her family, did a lot for her kids and her answer to everything was always, "But they're my kids," right.
A month from the wedding, I got --
I went to the office one Monday morning.
My husband called.
He'd gotten word that she'd had a massive heart attack and had died, and she was in her mid-60s.
She -- This question hit hard because this is an example --
My -- my friend and colleagues death is an example of someone that did care for everybody, always put her own health on the backburner.
We all fussed about her, and we got after her.
I personally got after her all the time about taking care of her own hypertension and issues.
But it also is an example of it happens to all --
We're all vulnerable, and I think Dr. Pinn said that.
This is a pediatrician.
She knew better, you know.
So she had the knowledge and still put her own health on the backburner.
So I think part of it is we're fighting in some ways evolution -- It's evolutionary.
I mean the other is the -- We -- we want the gene pool to --
to carry on and so I think women over the, you know, eons have always cared for their families.
We know mothers who've always put themselves, you know, or -- or putting women in general whether they're moms or not at putting the family first.
But then there's culture.
And culture eats strategy for lunch as we know.
And -- and I think there's just such strong cultural, you know. This is what women do.
We were the caregivers and so -- and that's the narrative.
I remember as a small child at hearing the narrative of my grandmother and my mother.
Quite frankly in my case, my mother was like, well, you know, it's a man's world and my grandmother was saying she shouldn't be playing with microscopes and chemistry sets.
She should plan to make toast for her husband someday, right.
I mean, literally, that was the narrative.
And as a very young child, I didn't buy the story.
But why was that?
Why did I not buy the story, but how many women do buy the story --
>> Right.
>> -- right?
They buy the story all the time.
So I think there's those kinds of issues, and then the other --
And Dr. Pinn hit on this, health literacy.
We're up against that.
I saw that in rural America when I practiced.
Women just -- I would have women coming in with end-stage breast cancer and their complaint was earache.
And they -- they weren't even aware.
I mean it was just shocking.
And so the health literacy and even knowing what, you know, what was wrong with their bodies was really power -- a powerful lesson for me when I first got to the county. And -- and then, you know, I think for women too, there's some self-esteem issues. We have things like depression that -- that is prevalent and they interfere with their health, and then trust of the medical profession I would add as well. So, I'll stop there.
>> Thank you.
>> I -- I -- You mentioned a few things in there, but I think as you'll find, we have different perspectives based on our backgrounds, theology/religion, rural equity, the ethicist among really the two ethicists among the group, and I was asked to really talk about the Hispanic population in many of my programs. I am Filipina, but I am 50 percent Hispanic, grandparent from Spain. But we have a lot of programs dealing with the Hispanic population. So what I'm going to share would be about the Hispanic population. And Dr. Pinn mentioned the social political aspects that is really besetting many of their program participants. At -- at the core of the primary challenge for this whole thing at the core of ethics is that values and beliefs of stakeholders. That was mentioned again and again. And so you mentioned culture, the beliefs. That is the even not just among Hispanics, among all the ethnic groups in the country, the value and belief of the stakeholder I think is the primary challenge. But for the Hispanic population, the culture, the barriers of language and transportation, we have many women who are pregnant who don't even speak the language and right there and then is a barrier to access. But then the how, how do we get them out of that -- the mental wellness, the lack of mental wellness, not only for women, for girls? But I truly want to emphasize also for men, because we're not going to be able to have a holistic reach to our women and girls if we're not going to involve the father's or the male partners in our efforts, but truly addressing that more comprehensive. When I talk about Hispanics along the border, we -- The -- the various issues, the lack of health insurance, the poverty level which is at one of the highest rates in the country comparatively, depression, 42 percent of pregnant women are -- have domestic violence and are abused. And then the Colonia's -- You know I cannot even imagine. We just had a global leadership conference of all the countries that PCI is in with the country directors being in Washington D.C., these past two weeks, and they were saying, "Well how do you look at the mother and child in the world?" And we -- and I say, "But take a look at the mother and child
in the border areas of our communities in Arizona, Texas, New Mexico.
They live in stables with a horse.
They don't have water.
They have to take their truck, if they have a truck and get water to bring home.
They still have an outhouse, so I mean we do in this country still have similar areas with many of the challenges that are in developing countries.
And when you took -- talk about the illegal immigration or the immigration per se, we won't even go to the politics of illegal immigration or immigration. But when you think about the undocumented population, a third of them have a child that is a US citizen.
So we need to really think about the impact on what Dr. Pinn said, political -- social political aspects. And I think at the very core of what we're going to be doing in the communities, that needs to be at the core of that and the value and belief of the stakeholders.

>> Okay, well I actually want to begin with something that you mentioned as well Judith, and that is the -- the perception that women are caregivers.
I think that we still need to talk about that a lot and how it ends up making such a difference in women's lives and even the way our logic around women giving care is not consistent with the logic that sometimes privileges men.
For example, one of the things that I thought about immediately was that there is an emotional element, but there is also a physical element, because giving care to some person means lifting them, changing diapers, making sure they have proper nutrition, etcetera. And there's a lot of heavy labor, but that gets connected with women, although we often think about distinctions between men and women around the issue of physical strength. But that is not taken into consideration when we talk about giving care.
One of the other things that I thought about immediately was the extent to which religion plays a role, and this is something that I'm always talking with students about.
Religion is interacting with almost everything. And it plays a role in the way we think about what women's responsibilities are, but even the notion of, and I'm going to push back a little bit on the idea of servant because especially in Christianity, there is a propagated the idea of being a servant and even a suffering servant that gets attached more to women I think than men because of the idea of service being something that women do, so there are theologies that are often being preached and persons on the ground sharing those at well -- as well that interact with the way we think about women taking care of themselves because the concept of love also in Christianity. But I think there are ways that they're --
they're connected to this and other religious traditions. I know Christianity more.
But the concept of love is also often thought of as not attending to the self, right, giving to the other, right.
So agape is understood as in some Theologians perspectives, flowing everything out of yourself to the other person and that there's something problematic in yourself as a Christian if you are attending to yourself. So our religion is as well.
A couple of other things I wanted to note were the ways that religion interacts with making it difficult for women to build bridges so that conceptions about who is a woman, especially in regard to queer and transwomen and the possibility of collaborating across the spectrum of women sometimes gets interrupted in terms of women attending --
>> Yes.
>> -- to themselves because of the inability to push against theological perspectives about who actually is a woman. And then finally for black women, I think the legacy of having black people, black bodies having been chattled, it interacts with the conception of servant and women because servant is also understood as person of color is black person, and I think that is in the psyche of all of us actually and something that we should talk about as we're pushing against this.
>> And -- and as we go to Kathy, just as you were saying it, because my whole life, my whole world is talking about sex and I love that, is the connection to the sexual identity, sexual health, sexual well-being and sexuality of women in connection to servitude. And that, whether it's through the historic horrors of slavery or even through the older context of marriage, why marriage existed, why we're in it, why we're not, what happens in terms of those gender dynamics. It's all still related to this sense of service servitude and prioritizing others --
So, and religion plays its own role in all of that.
>> And if I can just quickly add I think the -- that there is a deep connection to what's -- who is sex traffic and the idea of that being of service to persons who are the Johns.
>> There you go.
>> Yeah.
>> And I think that --
>> Just for you Kathy, that was --
>> Well I think riffing off of that is this idea of -- of trafficking and the social constructed of -- of servitude and sexuality is there's a normalization of it. And it becomes these categories like culture or gender. And then we use those categories in a normalized way in our research. So I think, particularly for Asian, Asian-American and Southeast Asian women in history, and I can't speak for all of the population, but I will offer what I know from my understanding of literature is, you know,
we have our histories of being human trafficked, whether it's comfort women -- Korean women with Japanese soldiers, etcetera. But often the research tends to look at it in terms of culture, Confucianism and shame. And it doesn't go beyond that. It doesn't push back beyond that. And we don't look at historical traumas. We don't look at human trafficking. So I come to this conversation doing a lot of community-based research [inaudible] action research alongside immigrant and refugee elders. And, you know, the suicide rate for Asian women over the age of 65 is the highest of all women of all races for -- for that age group. So a lot of the research might say it's because of obedience or because of shame factor or under-utilization of mental health services is because of this flat notion of culture. But what I get to do is I get to learn from immigrant and refugee elder women at the library about what are the difference social political dynamics of their health? I posted a prompt to some of the immigrant women, and they pushed back. Like we don't want to talk about what you want to talk about. But -- So we ended up talking about their biographies and their stories, and through the biographies and the history timelines, we learned about women who had been trafficked, women who had experiences with domestic violence in multiple countries, split family labor and emotional care. We learned about occupational safety health being seamstresses or work in the laundry. And through that process, we learned about access to healthcare because of -- because they're low wage. So part of it is they wrote their stories, and then those stories were the basis for grant writing. So I'm kind of looking back to thinking through conceptually how we need to have more complicated ideas of culture, and then also who tells us about this complicated ideas about culture. And perhaps from the populations we're trying to study can -- can have a seat at the table to unpack through their stories. >> I love that. Sister Love, we actually have a whole initiative called, "Everyone Has a Story." There's a whole video series, and it really is about the power of the lived experience to inform the programs, the service delivery, the policy work, the advocacy work. So thank you for that. And you actually started touching on the next two questions all in one Kathy, so I'm going to just move to you all at about 10:15. I'm just letting y'all know that now. That's my aim.
That's not my promise.
I mean, 11:15 -- I mean 11:15.
That's my aim, not my promise.
But -- So I'm actually going to throw the two questions
out together because I think you sort of already have provided
where the synergy is in there a little bit.
One is what are some of the most ethical approaches
or best practices in -- in --
in ethical approaches
for modifying some of these patterns?
Behavior and other factors.
And -- and then how can women
across that lifespan actually have a stronger voice
in decisions affecting their health?
I think those two things actually go well together
in that you started working on that a little bit Kathy.
So if you want to come in on some of that to continue
and then whoever else wants to jump in, that would be great.
>> So there's two ways -- When -- when I read this question,
I was excited about it in two ways.
And one is to think about the possibility
of democratizing research processes
and community knowledges.
So we have Dorothy Smith and Patricia Hill-Collins who talks
about situated knowledges.
And that's a valid form of evidence
to have our data informed decisions.
Again, I just get scolded by these "aunties" at the library,
but it's such a good practice as a researcher,
as an administrator, as a teacher.
And, you know, they have multiple ways
of sharing their understanding of what our social determinants
of health and how do we upend them,
through autobiographical cookbooks.
We've done poetry readings together
and in multiple languages.
So that's the one piece.
And the other piece is, you know, I am in higher education
and I have the -- the wonderful opportunity
of training researchers.
Most people who will go onto Med School
or critical global health, because I'm at LeBard School,
so it's more on the Bachelor's side,
and I think that's the big question
for me is really pushing my students
to ask what do they not know?
And what do they need to know?
And what are their positionalities that shape --
Maybe they universalize what their situated knowledge is.
So I think that's a question we have to ask ourselves
as we enter any community or any room or any research project
or any grant proposal, is what do I know?
What do I not know?
And how does that in fact impact my sets of questions
and how does that impact in what Dr. Warren said is my ability
to listen?
Because ideally from my perspective and training,
as a researcher is someone who can listen deeply with humility and with compassion.

>> Now, I'll pick up.

There is the listening piece that, you know, in the practice of medicine, a really key lesson is you start where the patient is at.

I mean that's the -- that's the starting point.
And that means you need to listen, you need to find out what their story is and understand that.
And so I think and I love what you do with your radio show because I was going to say on this --

I mean I think some of the approaches are using the media very creatively and getting more voices out there, that power of story is -- is so amazing in my own career, because I'm a public health practitioner.

I was a clinician that actually reached to the media when I was in Appalachia, because I wanted to get these voices out and be able to educate women.

The power of the media, that's how we rate the -- reach the masses, right.
And today, both with our social media, I think there's more creative ways that we can do that.

Obviously there's a dark side to the social media and we've seen that with bullying and so forth, but we need to get the positive I think in our films.

We should be influencing more of Hollywood in some of the films with our songs.

You know, when we look at -- at pop culture and so forth, what -- what are the messages that are getting out that we can do?

I also -- I wanted to touch on clinician bias, because I think we do need to recognize there's clinician bias and -- and we need to think about being -- being more forceful in our education of -- of clinicians whether it's physicians, nurses, nurse practitioners and pharmacists.

I mean you can go through the list, because there's -- there's -- I saw that a lot of the suspicion in role practice, the bias that --

that individuals had to the point sadly -- I --

I was actually told when I went into Appalachia to practice that I was the first physician that had treated them like humans.

And that was -- I got to tell you that hit me hard.

But I -- but kind of bridging into the second question for the stronger voice, I'll just kind of end with this.

You know, the -- When we talk about ethics, the tobacco industry has had some pretty unethical practices over the years.

And when I was health officer in Indiana, they came out with a cigarette, the Camel Number Nine that was focused on women, particularly young women.

And they would have parties, inviting young women to come and to have -- and give them free cigarettes along with doing their nails and their hair and giving them a Martini Number Nine and so forth.
This was all over the news back in the --
back in the probably about 2007 or so.
And so one of the things as a reaction to that, and I --
I think fear is a really -- That's a --
that's an emotion we've got to be very cautious
with because it can be very damaging, right.
But I think anger is something you need to harness,
and harness it productively.
And so as a health officer that had cared for young women
that had been addicted to tobacco
and then saw the consequences on --
on the birth and low birthweight, I hit the ceiling
when I heard about this.
And so we started something in very short order called,
Influence Women's Health in Indiana.
And -- and what we did is we started
by convening the most powerful women in the state
to educate them about what was happening.
And from there, we rippled through every --
We had events throughout every county
where women would come together
and they would tell their stories,
and they would be able to have dialogue.
And we -- we helped facilitate that.
And it was one of the most powerful things
that I look back on it.
Finally, and when I go back to Indiana, even the First Lady,
the -- the governor's wife always talks about what we did
and the legislator, so I think you've got to involve the top
and -- and the bottom, right, I mean, all across the spectrum
of women's voices, we need to get angry and -- and mobilize.
>> And I actually will pick up on involving the top
and the bottom and make a connection
to situated knowledge.
When I thought about this question, I use a lot of images
from the Civil Rights Movement and I thought
of Fannie Lou Hamer testifying before the Credentials Committee
She was a very unlikely person to be doing that, but she did so
and was able to do so because many people reached
into where she was in a variety of ways and brought her voice
into the conversation.
So, the situated knowledge is important, but there has to be
in terms of the ethics of -- of attending to --
to our persons and overcoming some of the patterns,
there has to be from the side of persons who have power
and access and influence, reaching in
and making possible getting that situated knowledge.
And it is not only about getting persons
from one place to another.
It also has to be about making sure that people who are talking
with each other communicate with one another and so issues
of hospitality are important,
even translation may be important, and it may be
that people have to learn each other's language.
But getting situated knowledge, and there's a lot
of work involved in that.
And if I think of the Department of Health and Human Services and its agencies. For example, as the entities to whom the question of ethical approaches are -- is directed, then I would ask, what are some ways that personnel can be directed toward getting situated knowledge from the most vulnerable persons who are the least likely to be a part of the conversations because there's information there that needs to be gotten into the conversations, yeah. >> Yes. Social media might be changing that a little bit. I just -- I know that even one of my physicians has their own Twitter handle and their own hashtag. And all you have to do is make a couple of the right comments, and you get reaction. >> Yeah, but -- >> Of course. >> -- I -- I actually think there are -- there are populations who are not even interacting at that point where there's knowledge to be, but I -- I agree, it is changing -- >> Absolutely. >> -- yes who's talking. >> And -- and -- and -- and as Maria comes in, I just -- I want to acknowledge your own acknowledgement of Sister Fannie Lou Hamer. And that of course for those who don't know, that's where we also get the standing moniker, "I'm sick and tired of being sick and tired," and I think that a lot of -- In -- in addition to her political activism, a lot of her harnessed anger also comes from the fact that she's a survivor of what we know as a Mississippi Appendectomy, which was forced sterilization on so many poor black women in Mississippi and across the south during that time. All of these issues are -- I mean, to go from forced sterilization to taking over the DNC are connected, but we don't have those conversations in public health spaces, where policy and implementation hit the road in our lives. And I think that she's a perfect example of what the voice, the questioning of the ethics and the movement around making change happen. Yes. >> And I'll follow through on what you just said, the policy and implementation connection -- so, and then the voice. But are we truly listening, Dr. Warren's question? Are we truly listening? I mean, we -- we go off and say, we're doing community-based participatory research, but are we truly doing community-based participatory research? Is that voice really at the table to -- to get that knowledge that we really need to do? I think we have come a long way but we have so much more to do.
And I wish I could do --
do the Energizer Bunny to where we're all already
in that energizer bunny, and we lead to the end
of the sci-fi movies, and I'm a movie buff.
But -- but talking about fast forward --
I mean, we can't even be doing things fast enough.
But when I looked at this question,
I was really looking at, yes,
Dr. Pinn showed the biomedical model,
but when I teach public health and health policy and law,
I look at that socioecological model.
At the center of that and at the center of anything
that we do even in servant leadership is that self --
that person at the center of that.
But are we really looking at all of those layers
and truly looking at an approach?
Perhaps we need to when we look at an approach,
look at every one of those layers, the self, the community,
the organizations, the environment,
and at the very core of that end cycle is policy and government.
Are we really looking at the policy and implementation
from the perspective of the voice?
So when I take a look at this in --
in addressing how do we get that voice from the women and girls
and people, one of the things that I would
like to really emphasize is that we need to address first
and foremost I think that mental wellness.
It is now this year, the lack of is now the leading cause
of disability in the world.
And we put it aside.
We don't have enough funds or resources allowing
for improving mental wellness.
But even then, at the very core of the programs that I have,
I don't do any program, one without the evaluation piece
and one with -- without involving the people
at the table to tell me how do I really want to reach them?
And then their voice is at the table.
But looking at what are those --
What are the things that I can do for people in the community
to help improve their lives.
And at the core of any program I have is life skills
and mental wellness.
That is the initial piece
that I do before I even do chronic disease prevention.
I look at teaching them how to budget, how to communicate;
what is that financial literacy like?
Where are they in their education?
What do they need?
Is it a language?
Where are the -- Are they in elementary?
Are they going to -- What -- what is that path like to get
to high school education?
Because we know that is attached to better health outcomes.
And so giving them the tools to get out of poverty,
teaching them how to save.
So those resiliency factors, resiliency tools is what I'd
like to share and really emphasize.
I was -- I was at the World Congress for Women's Mental Health in Dublin just six weeks ago, and even throughout the world when we're looking at anything that we're doing, we're doing all these approaches either on the treatment side, too late, kind of sometime, but not enough from the prevention side. But even then, at the very core is to really help people have that tool and factor as to being resilient, otherwise, they're going to continue in this very bad cycle of falling back and falling back and not truly emerging as the power and the voice that we need. And until they get that self-esteem back, that little bit of I am saving, I have this tool, I can go back to school, we're still not going to hear their voices. And even as much as we try to listen, we're not going to hear it because it's still going to be that whisper that's even beyond our -- our decibel hearing. >> So, I -- We're going to move to the next question and it -- But it's -- I want to segue it with continuing the conversation on women and stronger voices. And so I have this next place of not only understanding the whole issue around resilience and the resilient factor, but as someone who works with women who are survivors of violence, gender-based violence, other mental health issues, particularly dealing with HIV and sexual relationships and risk patterns and all of that is that what moves me and fascinates me the most about this work is the women who not only survive and -- and -- and our living the resilience, but then move from resilience to revolution where they actually become a part of the movement for change, whether they're going to school to become nurses or public health practitioners or advocates or activists in the community on behalf of others with the same or similar stories and issues. So, you know, in January, there were hundreds and hundreds and hundreds of thousands of men and people who love women and people who love us, who all showed up in Washington for whatever their issues were. And it was a myriad of issues that some was around anger, some was around fear, but people who had never found their voices before, found their voices, even if for a day or for, you know, another hashtag or a pink, you know, knitted cap. So the -- the question would be that in terms of the decisions that are made about women's individual health, what are some of the other ways that you are engaging those voices, not only on behalf of their own lives, but communities of women's health? What are some of the other ways that we're finding women find their voices? >> I'll -- I'll start. Thank you. I think one of the things that -- that I like with HRSA and CDC, the Maternal Child Health and the CDC, the racial -- the ethnic approaches to community health, the Reach Program to eliminate the disparities.
One of the mandates --
It's a mandate to actually have an infrastructure
in the community would -- called Community Action Network
and Collective Impact.
And the mandate is that the membership needs
to at least 25 percent of the membership in any network
or any group meeting that we have has to be
from the community and participants.
I think short of being mandated, we really must do it, but again,
that implication of a mandate, you have to do it,
because it's a benchmark.
You're being provided monies
that are very hard-earned dollars that you really need
to perform in these benchmarks.
And sometimes, that's the only way we're going to have --
we're going to make the changes is to make the mandates.
Because we can talk all we want
about community-based participatory approaches,
but unless we mandate that the voices need to be at the table
who are community members, who are participants, then we're --
we're not going to get that much ahead of us.
So to me, I -- We use that in the programs that we have is
that we follow the mandate with at least -- be nice if that --
if it goes -- the percentages go more than that.
At least 25 percent of the membership needs to be
from the participants themselves
and from the community themselves.
And I think that's when their voice is at the table.

>> So starting to talk about how we're changing our current
practices basically.
Yeah, go ahead Rosetta and then we'll do Kathy.

>> Okay, one of the things that I've --
I've been working on recently is actually not only with the US,
but a gathering of women in religions, plural, African
and African diasporan women.
And although the event --
the consultation begin in the academy, it is a consultation
of practitioners and scholars.
So, the voices of women in religions,
interacting with them, not only from the perspective
of what we do in scholarship, but also hearing their voices.
And the context of religion
or religions is an important context to hear women's voices
across the social strata.
And I think in addition to what we are doing or what I'm doing
in my own practice, I think it's an important place to consider
because the ritualizing that occurs in religious traditions,
the words that people hear and the things
that they do become a part of how they think the world.
So health agencies seeking places to interact
with the ritualizing person's lives I think is also an
important possibility for expanding their voices
because I know that what people hear in churches,
I hear them repeating and if it's something different,
they repeat it and it becomes a part of their way of thinking.
And I think that that can be done in regard to health
and caring for the self as well.
Absolutely, Kathy.

And I appreciate you talking about the way things are echoed and resonated in different spaces. And -- and hearing from this panel, I was thinking about it's more than just info and content delivery. It's also about that process of transformation, right. And I think you example of resiliency is, is it's an assets-based approach, right. So how do we -- how do we draw upon and water the seeds of leadership in different individuals? And that takes time.

And that takes a committed -- a commitment to a relationship, and we were talking about the earlier at the break. And -- and I think that doesn't always fit in a grant cycle. That doesn't always fit in a semester. And so I think that's that element of humility with that. So an example would be I was in a discussion group with again, the aunties of the library. And, you know, I had one prompt that was -- what -- what do people need to know about you that they don't know? And they spent about 30 minutes on what does that warden need mean? Is it need like food? Is it need like shelter? Is it need like access to -- to resources? And then I kind of got to the turn to needing that meaning in your humanization, what do people need to understand about you?

And one of the -- Two of the "youngerish" elder women said, "I don't get paid for what I do. So I don't know if I have a voice in my home."

And the elder woman said, "No, you were worth something," and this was all in English and then mixed with Chinese too. But they said, "You were worth something," and they kept on repeating that over and over. And that was -- ended up being the theme of their anthology. And I think that was that shift from info delivery to transformation, and then the opportunity to take a leadership role, and then now over time, we can set up the infrastructure to deepen that, taking that phrase, "You are worth something," and then adding onto that. I think that's that piece of it. It's not just adding voices and not just provide information, but sets basis for transformation leadership.

So, Judy I'm going to -- because I know you're going to respond to that, but I'm going to go ahead and throw this next question in so we can grapple with it for three or four minutes. And -- and that is, you know, it's a perfect place to come and land with the CDC Foundation is as we're talking about these current practices and these really granular stories of what it really looks like in the implementation space, in addition to how we're expanding, what are some of those resources needed to build the capacity for addressing some of these ethical issues.
that impact practice -- public health practice, research or even policies?
So some -- some worst things about the current landscape and then what are some of the resources to actually implement some of these innovations.

>> Yeah, so -- so that last question, the only thing I did want to highlight the clergy and the public health practice, we used the churches a lot in Indiana to magnify the message that we were trying to get across because it really makes a big, big difference. And then I think standardization too. Accreditation is an area that health departments now have accreditation and there's opportunity in that because that gets modified, and you'll -- refined are we learning the right things? But when we think about resources, so money, money, money.

Now that I've been at the foundation, I get that a lot. But it -- You know, its people, processes and technology are what we need and that does take resources. But we can be creative about our resources too. You know, I -- I wanted to mention this. I've loved the story now of how in rural communities, they're using like an uber-like transportation, but they're doing it with community members because they get the technology. It's like -- So sometimes it's not actually additional resources or -- or minimal resources can be done if we leverage the community at large. And then you give people even more involvement and purpose and might help with some of these other issues, those that might not be involved. But I think that expertise is one of the things that's needed, when we talk about resources, expertise at the right time at the right place as -- is important. I think case examples, I think people need again stories and I love case-based examples to help bring things together, communication as we all know. And then -- and all of this, we're talking about the analytical tools. And the -- and the analytical tools that are there for the practitioners. We got the -- the translation from research to practice. Where the rubber meets the road is so critical if we're going to really make a difference and have the implementation. So I think we need more tools in -- in regards to that.

>> Anyone else?

>> I had -- I have something to add.

>> Go right ahead Maria.

>> Sorry.

>> Yeah. So I'm going to go basic on this question about resources. Since time about 25/30 years ago, we looked at now what's called an evidence-based promotora model, which is the community health worker model.
That does not really expand it into all the ethnic groups. And there's 20 million, no, 20 different names for community of workers, patient navigate his family, navigators, whatever it is. I think at the core of resources, I want to just really emphasize the need for actually standardizing the community health worker model and I'm one of those proponents of -- of certification with the states. Not many states have looked at that, and the reason I say that is because it goes back to reimbursement and actually how do the people feel about the work that they do? I'm not discounting the community health worker work, that volunteer that goes and helps their family, the faith-based, but I still am not an economist, but I'm very much into economic development, those resiliency tools, give them something that makes them feel worthwhile or that worth that Kathy you talked about in the aunties of the library with the aunties. But, so community health worker model is actually being used now in many communities. I attended the communities Joined in Action Conference in San Antonio three months ago. And many models in the cities and counties look at multi-sectoral approaches, the libraries, the police, the -- the academic, the nonprofits, the people at the table so that multi-sectoral approach but at the core of that service delivery is the community health worker. And I think that needs to reach in all the different ethnic groups even if we looked at the evidence based initially on the Hispanic population, the evidence is there now that it is a valuable tool for improving lives through having someone from the community help provide that -- bridge that gap. So I really want to emphasize that because it's not enough that in 2016, only 48,000 community health workers were employed in all 50 states. That's not enough, because we need to reach those communities, and it's at the core of that service.

Thank you. I'm going to -- If you -- We're going to come back at the very end for folks that have some closing comments, but I want to really appreciate the thoughtful responses and really critical issues put on the floor. And I would echo the issue around the community health workers which is a worldwide issue in terms of respect and inclusion of that field. But I also want to throw in that most community health workers come through community-based organizations, which is another part, another layer. I'd be remiss if I didn't support my sector that is a whole other layer where there's so much potential
and so much opportunity for capacity building
and system strengthening that we get left
out from the research world all the way
to the implementation sciences and so I just want to make sure
that -- that community question writ large deserves
and should be getting a lot more of the investments financially,
as well as infrastructurally as possible.
So, with a round of applause, thank the panel
for our conversation thus far.
[ Applause ]
So we're -- Parting thoughts and --
and it can be in response if you like, but let's --
let's move through parting thoughts --
>> Okay.
>> -- one or three sentences or something like that.
>> It's --
>> I promise to keep us on time and now I'm a little bit over.
So --
>> -- kind of in response,
I wanted to not directly answer the question,
but to lift up again the idea of changing consciousness
and ritualizing what people do.
So I think the interactions with religious traditions
and religious communities is important at any level.
The creeds and confessions that are written and repeated
that sometimes get crafted at the local level and sometimes
at denominational
or organizational level is another way to interact
with what people are thinking just
as the curriculum is developed, those creeds go out
and are spread and -- and -- and that is one thing that I wanted
to lift up as a possibility.
The other thing I wanted to affirm was relationship building
and how important that is
and to underscore building relationships
with what may be unlikely communities and context.
And when I think about African-American women
and communities, I think the Black Lives Matter movement may
be an untapped resource in regard to --
Well, I don't know in regard to healthcare emphasis
for black women in particular.
Because the Black Lives Matter movement is very intentional
about looking at all of black life and being inclusive.
>> Interruption -- Did everybody see what Black Lives Matter did
for Mother's Day weekend?
Was everybody up on that?
>> No.
>> Raised money over the last month to bail out black mothers
from jail all over this country, hundreds, if not thousands
of women at the local level,
local organizations raised the funds
through the national messaging of Black Lives Matter
and they literally went and paid the bonds and baills of women --
mothers, sitting in jails for fines
for which they shouldn't be sitting in jail except
for the fact they couldn't afford the bond.
So if you gave money, there were women who were home
on Mother's Day because of you.  
So thank you for that.  
Sorry about that.  
That's how they can textualize it and become relevant.  
That's how they become relevant.  
> Well my parting words is I would like to thank everyone,  
CDC, Tuskegee and each and every one of you  
for having the opportunity for me to be part of this panel.  
But deeply, I want to thank each and every one of you  
for the work that you do.  
And I guess I want to give you a call to action to dig deeper,  
dig deeper, dig wider in your commitment  
to the work that you do.  
And I'm just going to quote a male, George Bernard Shaw.  
And I -- I feel this and I truly think about this: "The true joy  
in life is being used for a purposed,  
recognized by yourself as a mighty one."  
So it comes from us --  
> Thank you.  
> -- and we give, but it comes from us.  
> Yes.  
> Thank you.  
> So -- so I'll just end again.  
Thank you -- Great to be part of the panel.  
I -- I leave you with a thought or a question of what part  
of the problem do you own?  
And then what action can you take?  
> Yes.  
> That is so hard to follow, this panel.  

It's an honor to be part of this conversation.  
Maybe we should do a radio show together or something.  
> Thursdays at 6PM Eastern time, 89.3 FM and on the web.  
We stream live.  
> So it's -- The parting words are to think  
about cultural context in more complex ways.  
I think situated knowledge is in the context of power dynamics  
and the relationality of that.  
And then lastly is, you know, well not lastly,  
but it's the unconscious bias.  
What do we carry in our situated knowledges?  
Situation knowledge isn't just about marginalized  
under resource population.  
It's about those in dominant positions of power.  
The quick plug is I had suggested some readings,  
and they're on the CDC website and they're examples  
of the things that were -- we have been talking about here.  
And there are -- My colleagues have suggested readings as well.  
The last thing I'd say is, you know,  
to your great question -- mental wellness and  
mental illnesses drawing from Tenojan [Assumed Spelling]  
who is known as a theologian,  
but also his work during the Vietnam War  
in Vietnam was really public health and social work.  
And we must heal ourselves in order to heal others.  
So to center that balance and I think that's part of our task,  
our call and our hope for everyone is that we have peace
in ourselves, that we have peace in others.

>> Wow. And I just want to thank this panel. Please give them a round of applause. Thank you for your comments and questions. And I also -- I just want to acknowledge and be grateful. Intersectionality is a word that we have been working with in the Women's Reproductive Justice Movement for two decades. And we want to acknowledge that intersectionality is a term that's coined and defined by none other than Professor Kimberly Crenshaw, world renowned human rights attorney. And I just want to acknowledge and thank the CDC, because intersectionality has arrived at the Centers for Disease Control. Thank you.

[ Applause ]

>> So without further ado, we're going to ask Dr. Liburd to come and introduce our closing plenary speaker.

>> So what a full and powerful and rich day that we've had. I'm just excited about everything that I've heard today. I was tapping my foot through all of the presentations and I want to thank everybody who is still here, hanging in here to get us through the rest of our journey today. And I am very, very pleased and honored to introduce our closing keynote speaker, Dr. Melanie Nadeau. Melanie is an enrolled citizen of the Turtle Mountain Band of Chippewa in Belcourt, North Dakota, so she traveled all the way from North Dakota to be with us today. She graduated from both the Turtle Mountain Community High School and the Turtle Mountain Community College. She received her undergraduate degree in Psychology from the University of North Dakota and a Master's in Public Health in Community Health Education with a concentration in health disparities from the University of Minnesota. She recently completed her PhD in Epidemiology in the Social Behavioral Track Program at the University of Minnesota School of Public Health. She is a community-engaged scholar and has worked 13 years on various research projects within the American Indian community. There's a lot more that I can say about Dr. Nadeau, but I want to end by saying that she has a wealth of experience working in community health education and research and is dedicated to improving the health and well-being of Native communities. She has been married for 24 years and has one daughter. And in her free time, I don't when that is, right, she enjoys attending cultural events and hosting cook-outs with her family. So please join me in welcoming Dr. Nadeau.

[ Applause ]
Thank you so much.
And thank you for having me.
I'm so excited to be here.
It's been just great listening to everybody's thoughts.
And before I get started, let's see how do I bring this up here?
Can I just escape out of this here?
Okay.

Okay. So before I get started, I just kind of want to reflect
on the -- the summaries that were given
and just share some of my thoughts.
Health literacy seems to be a big issue,
you know in talking just from my community perspective.
I try to relay to individuals that are working in community,
that come into community and that want
to translate information back to the community, which is a step
that unfortunately gets skipped a lot of times,
and that's probably the most important step.
But when you're looking at health literacy
across the nation, you're going to see a second
or third grade level of health literacy on average.
So depending on what community you're working in,
it could be a little higher or a little lower than that.
And so it's really important that we're mindful
of when we're translating these resources
who we're trying to target.
Also, you know just thinking about cultural adaptation,
cultural adaptation of -- of current best practices,
current interventions, current resources, you know, it's --
it's -- We don't really necessarily need
to recreate the wheel here.
I mean, if we bring these resources community,
a lot of times, you know, people sit down and --
and put their own spin on it, and you'll end
up with a great product.
So I think that there's -- there's a lot of opportunity
in that -- that realm.
Another thing is that with digital storytelling,
that's something that's, like, hot on my --
in my arena right now.
I think that, you know, when you're working
with community members and having them share their stories,
people relate to people that are like them.
So when you're having someone share or you're trying
to change what's currently going on in the community,
having people that -- that the target audience can relate to,
it's very important.
And digital story is --
Storytelling is a very powerful way to do that, and at the close
of today, I'll share briefly a --
a little digital story with you that I did
on why I pursued public health.
Community engagement -- I mean, all of these things.
I think we're all on the same page here.
You know these community engagement --
I think we all understand the importance of that.
The -- But with the --
the messaging, the social media messaging,
I think that it's also equally important
to calendar the bad messages that are out there,
to take the time to actually counter those publicly,
because somebody said when I was in school,
working on my Master's way back then that the impact
of a bad message, it can take, like, ten years just to remove
that impact of that bad messaging.
So and how much of our efforts are actually going towards
"rebutting" these things that are out there that are true.
And I think too, you know, American --
especially with American Indian data,
the data is really weak right now.
There's just really poor data out there
for American Indians, you know.
They're -- You cant say there's really good data out there.
It's pretty bad actually.
And so, you know, but you use what you can.
And -- But I think that when we're presenting things
that we really need to stop and --
and share with our audience the strengths and the limitations
of that data that we're sharing so that you can say, hey,
this is really crappy data, but, you know, I want you to be able
to make an informed decision on whether
or not you want to use this data.
And I -- I -- I don't see that happening a lot,
and I think that, you know, as educators,
we need to take the time to share that with the community.
And the other thing
that I didn't hear mentioned here today,
but I think is a huge issue
from my community perspective is financial literacy.
You know, I'm a -- I'm first generation college student.
I still don't know how to handle money.
I come from a poor family, you know, so -- And how --
how does that impact one's health?
How does that impact one's financial ability?
How does that impact one's ability to stay in school?
And, you know, I know I'm not the only one.
And so, you know, I think that when we're talking about health
and improving the health of our communities that, you know,
I think something could come
from increasing the financial literacy
of our -- our communities.
Talking about community-based participatory research, I'm --
I'm a trained community-based participatory researcher.
I've done a couple of projects in that arena.
I think it's also important to --
We talk about it about as a approach,
you know, or an approach.
It's not an approach.
There's a lot of approaches
to community-based participatory research.
There's so many people put their own spin on it.
There's different ways of doing it, and so it really depends
on which -- whose approach you're following or whose --
whose literature that you're --
that you're using to drive your community-based approach
if you will.
But at the end of the day, it should be
in community informed approach, right.
And the other thing is
that there's also a reality-based approach,
and that's -- that is something
that was created by John Poupart.
He's from the American Indian Community and you know,
really focuses on the voice and storytelling of community.
So that's another approach to be mindful of.
And then, you know, the importance
of engaging our communities and the evaluation and the --
the creation of our assessment tools.
So, you know, everybody wants to take this tool and say, hey,
it's already been created.
It's -- it's -- its' evidence-based.
I don't have to do anything.
I just got to go give it to my community.
Wrong. That's not a good approach to do.
And I'll just offer up a simple example.
When looking at -- I worked on a tobacco project for a number
of years, and when looking at knowledge, you know,
our knowledge question or saying, you know bringing
in these cultural speakers around tobacco and saying, okay,
now you know everything about tobacco
from a cultural perspective.
You know the -- the positives and the healing
of the medicine of tobacco.
Now are you going to turn around
and share this with your community?
And we got the same answers, "No,
I'm not going to pre and post."
Well, was that a knowledge issue?
No. It was a cultural issue
because those people weren't the people that were recognized
in the community as the ones
that should be sharing that information.
So you have to be, you know, mindful of those things
so it's not necessarily a question that's going to get
at the answer that you're looking for.
And then the opioid epidemic --
I recently attended a Harm Reduction Summit, and, you know,
it's an epidemic all over the place,
on our tribal lands as well.
And, you know, one of the things that I think that we really need
to get an understanding on just
from a personal perspective is the policy differences
and the intervention differences and what we can do
as individuals, as -- You know, because clinical people can,
you know, help someone that's had an overdose, you know,
but I can't, well at least in the state of North Dakota,
but I can in the state of Minnesota.
So, like, understanding the differences, you know, what --
what are your -- what are you limitations?
What are you able to do?
Depending on state to state, learning from state to state differences, but also looking at state to tribal differences and, like, how does that impact the work that we're doing at a policy level? And then to reflect on the students, one of the student poster's breast cancer, you know, risk factors, I actually did -- That's what I just did my dissertation on. And, you know, as a community engaged scholar, I picked something in my community. I did a case control study in my community. It was over 400 people. In my sample, I reviewed, you know, medical records, radiology records all the way back. My first -- my first patient and my thing was -- sample was born in 1901. But at the end of the day, what did I find out? I did this case control study as a graduate student. That's, like, unheard of. It's kind of crazy, you know, like what are you doing? But I learned a lot working with an Indian Health Service. I learned a lot about, you know, how I could use data. And I had a community-driven project, and at the end of the day, I found out that this breast cancer risk calculator that is available on the National Cancer Institute site that providers used to inform their patients of their risk of breast cancer isn't relevant in my community because the risks -- those aren't the risk factors in my community. So I think that, you know, just not always assuming that those risk factors are the same in the -- in the communities that you're -- that you're working in and that things can change depending on where you're at. So that's kind of my reflection on all of your reflections. So, I'll go ahead and get started. Today, I'm just going to talk to you briefly. I'm going to try to make it quick about research considerations and tribal communities, sovereignty ethics and data sharing. And, you know, I always start out by talking about where I'm from, who my parents are. These are my parents. My mom is Shirley BlackEyes Belgard. My dad's Raphael Jack Nadeau. Seems like on the Indian country there, you always end up with a nickname. Somebody -- Everybody goes by their -- a different name. They're both from the Turtle Mountain Band of Chippewa Indians. It's one of many tribes in the United States. As of January 2012, there's actually 567 federally recognized tribes. And there -- In 2010, there were 324 federally recognized American-Indian reservations. So we're talking about a lot of different people here.
And the -- the thing that, you know, we need to stop and realize is that all these people are very different in culture language. And like I try to tell people, American Indians represent the smallest population in the United States. We're about two percent right now, but we represent the biggest diversity on this continent. Here's a picture of my dad. And this is actually my favorite picture of my dad. Here's he's sitting in front of a relocation sign. And relocation was and effort by the government to get natives off of the -- of their reservation out into mainstream society and to basically incorporate them into mainstream society. So, because of relocation efforts, there's a lot of people that ended up being urban natives, urban Indian population. And there's different numbers depending on where you're at geographically, but about half of -- about half of natives on average are -- are in the urban community. And my -- my dad, you know, he went out on this relocation program, and I mean, he was just, you know, just barely -- He just got out of the Army. He went -- he went and served in the Army. Then when he got home, he realized there was this program, so he went down to the bureau of Indian Affairs. And he went out to California, and I'm like, wow, you know. He was 21-years-old. He got a one-way ticket to California all the way from North Dakota. He didn't know where he was going, didn't know what he was going to, you know, what was at the other end. But, I mean, talk about brave, what a brave individual to do something like that. And but, you know, there was nothing, you know -- I was like, dad, why did you do that? He's like, because there was nothing. There was nothing, you know. I didn't have anything at home. I didn't have anything to go home to." You know, so we're talking about poverty, education, you know, employment, no jobs, no -- no -- We didn't have our tribal college back in that day, you know. My -- my dad said they lived way out in the bush. You know, they didn't have running water. They didn't have electricity. They went to town, and you know, they were lucky if they had a car that ran, you know. So -- so definitely dealing with some demographic challenges. And my parents, you know, I never really got to see them together because they divorced when I was 2-years-old and my -- my mother and my --
my siblings and I --
Well I actually stayed at my dad's unit I was seven.
But unfortunately, he end up having a heart attack
and also we had to go back to the reservation
and he, he, had diabetes.
And this is his mid-30s.
He was a -- you know, he was in his mid-30s.
And so, we had to go back to the reservation
so he could have access to Indian Health Service.
And so that changed everything.
So, this is the first time that I was, like,
exposed to that level of poverty on the community level.
You know I come from the city, and then all of sudden,
I'm sitting there on the reds, you know, on the reservation,
you know, so it's kind of shocking.
So, you know, here's some, you know, numbers for you.
The one's little dated, buy I'm you know,
sure they're still pretty much the same.
It's that coronary heart disease, well northern plains --
This specific to the northern plains.
We're more likely to report being diagnosed
with coronary heart disease and have a heart attack.
And then the American Indian/Alaskan Native adults are
also twice as likely as whites to be diagnosed with diabetes
and women were 2.3 times more likely
than non-Hispanic whites to die of diabetes.
So, a lot of disparities there.
And we have -- This is our Indian Health Service,
and we do have a beautiful facility.
But we, you know, we do have challenges when we're talking
about intervention and services
and what's available in the community.
And the, you know, the --
the dollars that are allocated per individual
for any in-health service are really low.
They're lower than what's advocated for federal prisoners.
So, you know, you're basically going to get better healthcare
if you go to prison than if you go to IHS.
And it's not because people are doing a bad job.
It's just that they're working
under a very stressed, underfunded system.
So what does that do to addressing issues?
So here's a picture of me when I was in the third grade and,
you know, they say that this is the age, you know,
that kids really start thinking about what they want
to be when they grow up.
And I knew, like, when I was a kid.
I'm like want to help my people.
I want to make a difference.
Like, I want to do something about this,
because I could see what was going on.
And, you know, I grew up with all this stuff,
so I have a very personal connection to what's, you know,
what -- It's more than just a statistic, put it that way.

And you know, here's some numbers for you,
American Indians/Alaskan Natives die at a higher rate, you know,
from chronic liver disease, unintentional injuries, assault, homicide, intentional self-harm, suicide, chronic lower respiratory diseases. We're also dealing with social challenges, violence trauma and loss. So looking at injuries, accidents, suicide, homicide firearms. Then, eventually, I'd go onto graduate from high school and I was a first generation high school and -- You know, it's a little odd to put that in your bio, you know, that graduated from the Turtle Mountain Community High School, right. But I'm really proud of the fact that I graduated from a tribal college and I'm really proud of the fact that I graduated from a tribal high school. And I think that that's a -- actually for me, it ended up being a good thing. It kept me grounded to -- to my community. And so as a -- as a first generation college student, I had a lot of things that -- that I'd end up having to face, and you know, just talking about educational disparities, the graduation rate, you know, American Indians you're looking at 82 percent whites. You're looking at 94 percent, so there's a huge educational disparity, be K through 12 for graduating. And then during my -- my school years, I started a family. During my undergraduate school years, I started a family. And, you know, unfortunately one of the things and I'm not the only one, but, you know, with the -- with students that come from communities that are impacted by a lot of stress socially, you'd -- you have to deal with that. Like, there's a lot of death. I've been going to funerals since I can remember, you know, and it's the life that I live. In fact, my brother-in-law passed away last week. You know, so it's just like then two days later, I'm graduating. You know what I mean? So it's like this -- It's just like you're always -- you're always operating in crisis mode, you know. It's -- It almost becomes second nature. But, this was the one that impacted me the most. My mother, she passed away from cancer. I took care of her until the day she passed. And this at the point when my life took a -- a totally different direction. I was like, do I really want to be a doctor, you know, a medical doctor? And this is what -- this is where I change my mind and ended up going into public health. So, you know, some stats for you. Death rate for malignant cancers for American Indian/Alaskan Native persons, it's 338 per 100,000 compared to 220 -- 223.4 for whites. Here's our college. So, I was very fortunate when I moved back to the reservation
to regain financial stability after my mom passed that --
that I had a tribal college here to attend.
And this is actually where I discovered my first mentor.
I ended up taking a Genetics class
with Dr. Lyle Best.
And he graduated at -- I mean not graduated.
He retired as a clinician, medical doctor in my community
at the Indian Health Service,
and he was actually the medical director at one point.
And he's not native but he's is --
he was very vested in our community
and he actually got a -- a grant to conduct a genetics
in preeclampsia study with the women in our community.
And it was really good because it wasn't community-based
participatory research because the community did not pick the
topic, you know.
So now, at, like, the center that I run, we're moving
to the point to where we're trying to work with tribes
to create -- to create agendas -- health -- you know, what --
what do they want to address?
So research agendas and so that you can match the researcher
with the research agenda so that it's more meaningful partnership
instead of the researcher coming in and say, "Hey I want
to do this," and it doesn't make sense to the community.
So -- But, aside from the community not picking the topic,
a lot of the components
of his project had community-based participatory
research characteristics.
And just to name a few is building infrastructure
at the college so that we could do genetic research,
working with elders in the community,
translating information
at multiple levels of the community.
So he did a lot of things like that.
So -- And here's some statistics that I wanted to share.
And, you know, one of things, like if you look at, you know,
our community graduation rates compared to national rates,
we're not doing as well, right.
But the when you break it down,
and this is specific to my community.
It'd be totally different for another native community.
But for my community what we're seeing is
that our men are not doing very well.
Like, so when you start breaking those statistics out,
you know, our men are sicker.
Our men are, you know, not graduating
at the -- the higher rate.
And so when we talk about wellness of women and children,
you know, I -- We need our men.
We need our men to be well.
We need our men to be brought to the table.
And I hear that a lot in the community, you know, with the --
with the community efforts
that we work visiting with the tribes.
So, but the Tribal College is
where I started my research journey.
And the first thing I heard is, we've been researched to death.
And I'm sure everyone's heard that one before. And some of the, you know, concerns are that the results aren't interpreted in a language or formats that -- that are appropriate and we talked about that. You know, coming in the community, there's a lot of work. I sit on the Turtle Mountain Band at Chippewa Indian's Research Review Board, and in that role, you know, people will come and propose research to us. And, it's like have you talked to anybody in the community? Have you -- have you brought letters of support, like you have a great idea, but is it -- is it feasible? Oh, we didn't do that. Well, okay. Somebody goes over to Mental Health and Mental Health, oh, no, we don't -- we can't, you know, we're working in crisis mode. We barely have any -- enough staff to see our patients. Let's do a project on the side. So and that doesn't always happen, but it's just being mindful of, you know, what's currently going on in the community history demographics, the history of research in a particular community, cultural, traditional versus nontraditional, the etiquette, you know, just encouraging the community involvement, be prepared for possible community consent. With our board, we actually review everything, so even if it's not research, we review it. We review everything coming into the community because it -- We're -- You know, we're at a point to where and maybe that won't always be so, but we're at a point to where it's like how do you sit there and make an informed decision whether or not something's research or not if you didn't review it? And then just raising that awareness about what's going on, hiring, you know, people from the community to actually to do the work, respecting community protocols. And you know just -- just really -- just taking a minute to say, you know, community considerations are not always the same as individual academic research considerations. They're -- they're different. So one example I could give is up in Alaska, there -- there were so many communities that were selected. It was randomized clinical trial from my understanding. I really don't know the work that well, just so, forgive me for that. But, so they -- they selected so many American Indian communities to get the TB vaccine that they were testing, and they selected so many to not get it. And my community was a control group. Well, I ran into a lady in Alaska. She was a descendant from someone from her community and that -- they were -- they were actually -- they actually got the -- the vaccine. So -- But what -- what went wrong there? Well what went wrong is the vaccine was very successful,
but then it wasn't turned around and administered community wide. So then the community was pissed off. See, so did the researchers do anything wrong from their standpoint? No, not necessarily because they were operating from an individual academic perspective, you know. But the -- From a community perspective, that was wrong. So, you know just -- just taking the time to -- to realize that those things don't always align and the when you're working on a community level that -- that doesn't, you know, that those -- those -- those are things that need to be taken into consideration.

Also, you know, just really taking the time to say, did we get it right with publications, presentations, results. Everything that I do goes through my community before I publicly talk about it. So, it's just a good -- it's just a good way to be anyway. And then, you know, just talking about from the -- my standpoint as a student, as doctoral student, you know, my classmates had to get an approval from the Institutional Review Board at the University of Minnesota. Well, since I was working with my tribe, I had to get approval from the University of Minnesota Institutional Review Board. I had to get an approval from the Aberdeen Area Indian Health Service Institutional Review Board, which could've determined that I would've had to get a national one, but they said that I didn't have to, so that was good. I didn't have to get that extra one. I had to get approval from the Turtle Mountain Band at Chippewa Research Review Board. I had to get a resolution passed with my tribe, and I had to get a Letter of Accommodation from the CEO of the Indian Health Service. So, it's kind of different when you're working at that level, but it's good. It's good. I think it's -- it's important to have those levels of approval as well. And you know, just understanding that it's important to build these meaningful relationships, being culturally competent. And this is, I like -- This goes for, like, American Indian to American Indian even, like, you know, I -- I might be competent with my own people, but that doesn't mean I'm competent with the tribe down south. So, if I'm working in that community, I have, you know -- If I want to work in a good way, then I want to attend anything that I'm welcomed to, you know, so that I can get to understand the -- the ceremonies, the community activities, the service activities, the volunteer opportunities, everyday activities that are occurring
in that community as well. And, you know, just really trusting the community in that they know what they need and they know how to get it done and they know what it takes to make their communities healthy. So, when producing projects, it takes a lot of time -- I mean products for American Indian Tribal audiences, it takes a lot of time. And I'll use one example. There's organization that approached my center and they said, we want to make sure that our materials are culturally competent. I'm like, okay. And so they brought them in, and my team, we do everything on a team-based approach. And so we -- we make decisions as a consensus because that's a traditional way of doing that in our region and so we don't move forward on anything unless we all agree. And so when reviewing these materials we were, you know, kind of laughing because it was not one of those pictures of those individuals on these materials, like, looked -- They weren't from our area. They were, like, from different tribes, you know what I mean? And it's like no, no, no, no, no, no. So then they went back to the drawing board, and they came back again, and I think the second rendition was worse than the first one, you know. So I was like, oh my gosh. So anyway, so now they're going to have a campaign to do some pictures from people from our communities to include in their cancer resources. So it's like, yes, that's the way it should be. So, incorporating the local knowledge and traditional knowledge is very important. And I'm not sure how I'm doing on time here. But anybody have -- idea how much time I have left? Five minutes? Okay. So, yeah just take -- taking the time to do things right. And then we talked about community-based participatory research. So, you know, just talking -- And I touched on some of these things already. Research in American Indian community is so -- A lot of, you know, from my community, our board's only been, you know, in existence for a couple of years now, you know. So we're learning a lot through the process of having our board and just making sure that -- that we're regulating the projects that are coming in, reviewing everything, using a checklist to make sure that the -- the -- that everything's in compliance, passed and resolutions with the tribe, that our team possesses the professional qualifications that required, you know. And we do that because we -- we -- we -- we videoconference, so we're able to meet.
So it's not like people have to be in community. You know, so just taking advantage of technology in order to make these things happen especially in rural communities is -- is a very good way to go. Tribal possession of the data is very important to prevent misuse. And I haven't come across where they said, no you can't use it. It's just mainly just being a good, you know, being -- just informing -- informing the community what you're doing. And you actually end up getting some really good advice on -- on how to move forward, so it works out pretty good. So, yeah, and, you know, just from American Indian community perspective, just making sure that you know who the researcher is, what research they have done, why do they want to do research in your community? You know, we have people approaching us from all the way across the country. Why? Why do you want to do research? It might be a very good reason. But why are you want -- Why do you want to come all the way over here and do research right here? And does that -- and does your reason, you know, make sense for our community? And is it going to benefit our community? So and a lot of these are reciprocal in nature, but you know, just -- just -- just being informed basically of the research and making sure that the researcher's reporting back and reporting to community, not only reporting back, reporting out to community and translating that information at multiple levels so that it's actually useful to the community. And they can take that information and use it in reports, use it in grant writing, etcetera or use it for social, you know, to change social norms. And then, you know, asking them, do you want to be identified in this publication? Some tribes don't want to be. Some tribes say, yeah, of course we want to be recognized for the -- the work that we contribute too, you know, that's another consideration. So -- so in conclusion, the best way for American Indians to ensure that they're not harmed by and benefit to the greatest extent from the research is to be involved throughout, and I'd say this is true for any community. And this is a picture of our elder's group. They actually overseen our project at the Tribal College and it was really -- really good. And, you know, I think nothing that -- Probably stayed home with me the most is that once they were done, they went into lab, they learned how to pipet and do genetic analysis. They listened to our spiel, all that good stuff. But then they turn around and they said, okay, we want you to talk to us about cancer. We want you to talk to us about diabetes.
We want you to talk to --
we want you to explain to us what fragile X syndrome means.
So, you know, and realizing that the work
that you do is not only about you.
You become a resource to those individuals in the community
and that you're expected to step up and fill
that role even though it might not even have anything to do
with the work that you're doing.
And then I'm just going to finish
by playing this little video for you that I --
that I created on why I chose public healthcare.
[ Tribal Singing ]

Here's a picture of me in the third grade.
At this age, I started thinking
about what I wanted to be when I grew up.
This is a picture of my Uncle Benny, dad, mom and Uncle James.
My Uncle Benny died from an unintentional injury,
my mom from cancer and my dad lives with diabetes.
Both of my grandparents passed away from cancer.
My Uncle Beatty and his daughter, Ivy, were shot
and killed by the same bullet.
My Uncle Edward passed away from cancer.
Eventually, I would go onto college
as a first generation college student.
Experiencing all of this loss motivated me
to pursue a health career.
My Uncle Bernard passed away from an aneurysm, my cousin,
Bernard Junior passed away from cancer.
My stepfather passed away from an unknown cause.
My Uncle Francis died of asphyxiation.
Right before I graduated with my Master's degree
in Public Health, my father had a toe/partial foot
and a below the knee amputation due to his diabetes.
I'm happy to report that it's been four years
since his amputation.
His first prosthetic leg says a lot about his personality.
It has lightning bolts on it.
The fall of 2010, I entered into the PhD and Epidemiology Program
in Social Behavioral Health.
[ Tribal Singing ]

Well thank you.
[ Applause ]
>> So let's give Shauna a round of applause.
[ Applause ]
Yeah, we -- I just want to say in conclusion
of a wonderful day, we started out at the beginning
of this year to pull together this forum,
and I couldn't be more pleased with how the day has turned out.
We have been challenged on many fronts
over the last several months, but we came in this morning
with smiles on our faces, because we saw all of you here.
And so I just want to thank you.
I want to thank all of our speakers, our facilitators,
everybody who participated in today's program.
And I hope that you will carry what you heard today both
with you and your heart and in your minds. 
And consider it seeds planted that we are looking to water 
and then to see a great harvest, so thank you for being here. 
[ Applause ]

>> The thanks go far and wide from my context, 
but start with Dr. Liburd and Dr. Tucker. 
I think you need to know that coming together 
of these two issues in -- 
in times such as these was phenomenal. 
And they made a commitment 
to make it happen and it's happened. 
So I want to publicly thank both of them. 
[ Applause ]
And the partnership and I'm intentional about talking 
about the difference between relationship and partnership. 
The partnership that we're enjoying and growing 
with the Centers for Disease Control and Prevention is -- 
it's a work in progress that requires attention every day. 
And Jo Valentine gives it attention every day, 
and I want to thank her as well. 
[ Applause ]
And then you've heard the -- the cliche the media is the message, 
and there's -- there's been one message -- 
message bearer for the National Center for Bioethics 
and Research and Healthcare, because so much 
of what you hear is not true. 
So much of what you see is not true. 
So much of what you've heard is just wrong. 
And I wanted to thank Dr. Joan Harrell for assuring 
that the message that you're hearing about, 
these events is true, is correct and is consistent. 
Dr. Harrell, thank you so very much. 
[ Applause ]
And I'm not going to take any more time thanking folk. 
I just want to thank y'all. 
But the issue for me is about women not mother, grandmother, 
wife, daughter, granddaughter, aunt, uncle, not uncle. 
I got caught up. 
But it's -- it's not about the social role of women. 
You know, I -- I -- I don't know the right words, 
so I won't use it. 
I know the right word. 
I won't use it, but maternal child health. 
I've been working in public health for many years 
and I've shuddered when I hear maternal and child health 
as if women are connected to mothers only. 
And we were intentional about listening 
as I started off talking this morning, and -- 
and this forum was about women and girls, 
not their social role, just to be a woman 
and to be girl is what this forum was 
about for her whole life. 
So I wanted to thank you all for listening 
and hearing I hope about women. 
And the office, let me get the office right,
Public Health Ethics at CDC is really important. It's a courageous step to say that Public Health Ethics is different than Bioethics. It's important paradigm shift that's still in progress and I think the, both leadership in that office is really -- Drue Barret, [inaudible] have done an outstanding job in making a distinct difference not good or bad, but different. And as public health ethics grows, you'll learn more and more about that difference and appreciate it I hope. So I want to thank you two particularly for your courage to bring this new paradigm into fruition.

[ Applause ]

And last and most importantly from my context and a historical context, I want to thank Booker T. Washington for his courage and wisdom and vision to say that we all ain't the same. And -- and that's okay. But we're all equally as important, and that's okay. And his courage to say something then that many times we don't have the courage to say now is that we need to target those who are in greatest need with all of our resources. He's done that and -- and you see the results of that. And again, minority health month started with Booker T. Washington. And I want to thank you all for having the courage to say that loud and clear for those who didn't know. And now they don't even have to say they didn't know. All they can say now is Minority Health Month started with Booker T. Washington Negro Health Week. So as we close, and lastly you know, what we said two years ago. This is an annual event. And unfortunately we have so many vulnerable populations, so we don't have a problem with figuring out who to target because a vulnerable populations continue to grow. So I look forward to the day when we won't have to talk about public health ethics and target populations, because ethical issues will be applicable to everybody. And they won't be equal. They'll be equitable and I hope now you know the difference. Thank you so much and we'll see you this time or soon next year.