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EXPECTING MORE: ADDRESSING AMERICA'S MATERNAL AND INFANT HEALTH CRISIS

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH, EMPLOYMENT, LABOR, AND PENSIONS

AND THE

SUBCOMMITTEE ON WORKFORCE PROTECTIONS

OF THE

COMMITTEE ON EDUCATION AND LABOR

U.S. HOUSE OF REPRESENTATIVES

ONE HUNDRED SIXTEENTH CONGRESS

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C O N T E N T S

Page

Hearing held on October 23, 2019 1

Statement of Members:
- Adams, Hon. Alma S., Chairwoman, Subcommittee on Workforce Protections 6
  - Prepared statement of 7
- Walberg, Hon. Tim, Ranking Member, Subcommittee on Health, Employment, Labor, and Pensions 4
  - Prepared statement of 5
- Walker, Hon. Mark, Ranking Member a Representative in Congress from the State of North Carolina 7
  - Prepared statement of 8
- Wilson, Hon. Frederica S., Chairwoman, Subcommittee on Health, Employment, Labor, and Pensions 1
  - Prepared statement of 3

Statement of Witnesses:
- Crear-Perry, Dr. Joia, MD, President, National Birth Equity Collaborative 36
  - Prepared statement of 39
- Sankofa, Ms. Nikia, Executive Director, United States Breastfeeding Committee 24
  - Prepared statement of 27
- Stewart, Ms. Stacey D., President and CEO, March of Dimes 9
  - Prepared statement of 12

Additional Submissions:
- Chairwoman Adams:
  - Prepared statement from A Better Balance 90
- Courtney, Hon. Joe, a Representative in Congress from the State of Connecticut:
  - Letter dated January 27, 2020 from Locke, Mr. Caleb Andrew 94
- Jayapal, Hon. Pramila, a Representative in Congress from the State of Washington:
  - Letter dated July 10, 2019 95
- Johnson, Hon. Dusty, a Representative in Congress from the State of South Dakota:
  - Article: Effort Begins To Reduce Risk of Death of S.D. Mothers During Childbirth 98
- Morelle, Hon. Joseph D., a Representative in Congress from the State of New York:
  - Letter dated January 28, 2020 from Johnson and Johnson 110
- Scott, Hon. Robert C. "Bobby", a Representative in Congress from the State of Virginia:
  - Letter dated January 27, 2020 from National Association of County and City Health Officials (NACCHO) 111
  - Letter dated January 27, 2020 from undersigned orgranizations 113
  - Prepared statement from Abbott, Mrs. Becky M. 115
  - Link: Sexual Abuse To Maternal Mortality Pipeline 127
- Stevens, Hon. Haley M., a Representative in Congress from the State of Michigan:
  - Letter dated January 27, 2020 from National Foundation for Ectodermal Dysplisias (NFED) 128

Page

Additional Submissions—Continued
Takano, Hon. Mark, a Representative in Congress from the State of California:
Article: Medicaid Expansion Fills Gaps In Maternal Health Coverage Leading to Healthier Mothers and Babies 130
Underwood, Hon. Lauren, a Representative in Congress from the State of Illinois:
Prepared statement from Mom Congress 142
Prepared statement from The American College of Obstetricians Gynecologists 144
Prepared statement from 2020 Mom 151
Link: Eliminating Racial Disparities In Maternal and Infant Mortality 153
Chairwoman Wilson:
Prepared statement from American Dental Association (ADA) 154
Prepared statement from American Society of Plastic Surgeons .....
Questions submitted for the record by:
Schrier, Hon. Kim, a Representative in Congress from the State of Washington..... 161, 163, 165
Ms. Underwood 163
Responses submitted for the record by:
Dr. Crear-Perry 166
Ms. Sankofa 171
Ms. Stewart 177

EXPECTING MORE: ADDRESSING AMERICA'S MATERNAL AND INFANT HEALTH CRISIS

Tuesday, January 28, 2020
House of Representatives
Subcommittee on Health, Education, Labor, and Pensions
Joint with
Subcommittee on Workforce Protections
Committee on Education and Labor
Washington, D.C.

The subcommittees met, pursuant to call, at 10:19 a.m., in Room 2175, Rayburn House Office Building. Hon. Frederica S. Wilson (Chairwoman of the Subcommittee on Health, Education, Labor, and Pensions) presiding.

Present: Representatives Wilson, Adams, Courtney, Fudge, Takano, DeSaulnier, Norcross, Jayapal, Scott, Morelle, Wild, Harder, McBath, Underwood, Shalala, Levin, Omar, Stevens, Trahan, Walberg, Roe, Walker, Fulcher, Mueser, Johnson, Keller, and Foxx.

Also Present: Representatives Bonamici and Schrier.

Staff Present: Ilana Brunner, General Counsel; Sharon Crowder, Health Policy Fellow; Emma Eatman, Press Assistant; Daniel Foster, Health and Labor Counsel; Alison Hard, Professional Staff; Carrie Hughes, Director of Health and Human Services; Ariel Jona, Staff Assistant; Stephanie Lalle, Deputy Communications Director; Andre Lindsay, Staff Assistant; Jaria Martin, Clerk/Special Assistant to the Staff Director; Kevin McDermott, Senior Labor Policy Advisor; Max Moore, Office Aid; Udochi Onwubiko, Labor Policy Counsel; Veronique Pluviose, Staff Director; Ivorie Stanley, Labor and Health Policy Fellow; Banyon Vassar, Deputy Director of Information Technology; Joshua Weisz, Communications Director; Cyrus Artz, Minority Parliamentarian; Courtney Butcher, Minority Director of Member Services and Coalitions; Akash Chougule, Minority Professional Staff Member; Cate Dillon, Minority Staff Assistant; Rob Green, Minority Director of Workforce Policy; Jeanne Kuehl, Minority Legislative Assistant; John Martin, Minority Workforce Policy Counsel; Audra McGeorge, Minority Communications Director; Alexis Murray, Minority Professional Staff Member; Carlton Norwood, Minority Press Secretary; Ben Ridder, Minority Professional Staff Member; and Kelly Tyroler.

Chairwoman WILSON. The Subcommittees on Health, Employment, Labor, and Pensions and Workforce Protections will come to order.

Welcome, everyone.

I note that quorum is present, I note for the subcommittee that Congresswoman Bonamici of Oregon and Congresswoman Schrier of Washington are permitted to participate in today's hearing with the understanding that their questions will come only after all members of the HELP and Workforce Protections Subcommittees on both sides of the aisle who are present have had an opportunity to question the witnesses.

The subcommittees are meeting today in a hearing to receive testimony on addressing our Nation's maternal and infant health crisis.

Pursuant to Committee Rule 7(c), opening statements are limited to the Chairs and the Ranking Members. This allows us to hear from our witnesses sooner and provides all members with adequate time to ask questions.

I recognize myself now for the purpose of making an opening statement.

Today we are gathered for a bipartisan hearing to discuss our responsibility to address America's maternal and infant health crisis. During this hearing we will confront the troubling reality that the United States has the worst maternal mortality rate among developed countries. Each year 700 women die from pregnancy-related complications and 50,000 women suffer from life-threatening pregnancy-related complications. Even as our peer nations across the world make significant improvements in maternal and infant health, outcomes in the United States are moving in the opposite direction. In fact, the U.S. maternal mortality rate in 2016 was nearly 17 per 100,000 live births, more than double the rate in 1987.

This impacts communities across the Nation, including my own. In Florida, the situation is even more severe. The maternal mortality rate is 22.3 deaths per 100,000 live births, well above the national average. Miami-Dade County had a maternal mortality rate for Black women of 34.3 in 2018, more than double the national average for all mothers. These numbers are unacceptably high.

Improving maternal and infant health requires us to focus not just on the health of mothers during pregnancy, but on their overall health. That means providing consistent quality and affordable health insurance to the roughly 11 percent of reproductive age people, 10.6 million Americans who went without health insurance in 2017.

Fourteen states still have not expanded Medicaid eligibility, which pays for 43 percent of births, to cover more low-income people. In those states, women may lose their insurance just two months after giving birth. It means supporting the Special Supplemental Nutrition Program for Women, Infants, and Children, or WIC, which has proven to help protect the health of both mothers and infants by providing breastfeeding support and helping mothers avoid preterm births.

A recent study found that infants born to WIC participants are 33 percent less likely to die than non-participants. Despite this track record, WIC saw the lowest number of participants in over a decade in 2016. Instead of restricting access to quality health care, Congress must pass legislation to expand access to programs,

like WIC, that have helped mothers navigate healthy pregnancies for decades.

Finally, and most importantly, addressing the maternal and infant health crisis means undoing structural racism that affects every facet of American life, from health care to housing to education and transportation.

Black mothers are three to four times more likely to die from pregnancy-related complications than White mothers, regardless of their education and income. Native American mothers are two to three times more likely to experience maternal mortality than White mothers. Simply put, if we are to stop this crisis we must all work together and address the complex issues in maternal and infant health.

That is why I am pleased we have an opportunity today, with the help of our witnesses, to discuss how we can make meaningful and immediate steps to improve maternal and infant health for all people. I look forward to today's bipartisan discussions and thank our witnesses again for joining us.

[The statement of Ms. Wilson follows:]

Prepared Statement of Hon. Frederica S. Wilson, Chairwoman, Subcommittee on Health, Employment, Labor, and Pensions

Today, we are gathered for a bipartisan hearing to discuss our responsibility to address America's maternal and infant health crisis.

During this hearing, we will confront the troubling reality that the United States has the worst maternal mortality rate among developed countries. Each year, 700 women die from pregnancy-related complications and 50,000 women suffer from life-threatening pregnancy-related complications.

Even as our peer nations across the world make significant improvements in maternal and infant health, outcomes in the United States are moving in the opposite direction. In fact, the U.S. maternal mortality rate in 2016 was nearly 17 per 100,000 live births—more than double the rate in 1987.

This impacts communities across the nation, including my own. In Florida the situation is even more dire. The maternal mortality rate is 22.3 deaths per 100,000 live births – well above the national average. Miami-Dade County had a maternal mortality rate for black women of 34.3 in 2018 – more than double the national average for all mothers. These numbers are unacceptably high.

Improving maternal and infant health requires us to focus not just on the health of mothers during pregnancy, but on their overall health.

That means providing consistent, quality, and affordable health insurance to the roughly 11 percent of reproductive age people—10.6 million Americans—who went without health insurance in 2017. Fourteen states still have not expanded Medicaid eligibility, which pays for 43 percent of births, to cover more low-income people. In those states, women may lose their insurance just two months after giving birth.

It means supporting the Special Supplemental Nutrition Program for Women, Infants, and Children, or WIC, which is proven to help protect the health of both mothers and infants by providing breastfeeding support and helping mothers avoid preterm births. A recent study found that infants born to WIC participants are 33 percent less likely to die than non-participants.

Despite this track record, WIC saw the lowest number of participants in over a decade in 2016. Instead of restricting access to quality health care, Congress must pass legislation to expand access to programs, like WIC, that have helped mothers navigate healthy pregnancies for decades.

Finally—and most importantly—addressing the maternal and infant health crisis means undoing structural racism that affects every facet of American life, from health care, to housing, to education, and transportation.

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have an opportunity today, with the help of our witnesses, to discuss how we can take meaningful and immediate steps to improve maternal and infant health for all people.

I look forward to today's bipartisan discussions and thank our witnesses, again, for joining us.

Chairwoman WILSON. I now recognize HELP Ranking Member, Mr. Walberg, for an opening statement.

Mr. WALBERG. Thank you, Madam Chairwoman.

Today we are here to discuss the critical issue of infant and maternal health, and in fact to I would hope to exalt motherhood and birth itself.

While women around the globe are dying less from childbirth, here in the United States the rates have been climbing. Other countries with rising maternal mortality rates, Afghanistan, Lesotho, and Swaziland. For black women, the statistics are even more troubling. According to the World Health Organization, the maternal mortality for black women in the United States are the same for women in Mexico, Uzbekistan, and this is unacceptable.

This issue, a matter of literal life and death for women and babies, demands a serious and thoughtful response. The exact causes of the United States' high maternal and infant mortality rates are unclear and varied, but they can be known.

The HELP subcommittee has jurisdiction over employment-related health benefits and the Employee Retirement Income security Act, otherwise known as ERISA. So as we study the important issue before us today, and before this committee considers the imposition of additional government mandates that could have unintended consequences on employers and employees alike, we should closely examine this problem through separate hearings about the larger issue and propose legislative solutions.

As we have learned from experience, one size fits all government requirements more often than not compound the problem. That is why specific policies from this committee and Congress must involve a thorough review of the current problem and a recognition that community, individual, and family engagement are also key components which need to be recognized and addressed.

Let us not forget the important role employers are playing in providing health insurance to mothers and babies. Because of our strong economy more workers have access to high quality affordable health insurance at work. The most recent Congressional Budget Office numbers indicate that 159 million Americans are covered by employer-sponsored coverage. In addition, maternity benefits are often the largest type of health care expenditures for employers. Because of this, employers proactively offer a number of programs aimed at increasing quality and lowering cost for employees, and another reason for an encouraging economic growth and employment.

Many employers offer programs for fertility, prenatal care, neonatal and premature birth medical care, lactation consulting, and transparency tools to view provider and hospital quality metrics as well. Employers also rely on payment and delivery model reforms to reduce scheduled preterm births, direct high-risk patients to high-quality providers and hospitals, or lower costs by offering bundled payments to providers for childbirth services. Milk delivery

services have also gained popularity with employers by offering convenient shipping services for employees who travel for business.

While employers, communities, and families are play a pivotal role in decreasing maternal and infant mortality rates, we must also ensure that Congress is taking the necessary steps to guarantee the safety and wellbeing of women and newborn and unborn infants. We should promote policies in Washington that encourage a strong family, allow families to flourish, and protect life at all stages, from conception to natural death.

I know that both sides can agree that maternal and infant health is an issue worthy of attention. And it is my hope that we can hold additional legislative hearings on any proposed solutions and that any subsequent legislation can be considered in a bipartisan manner. I certainly commit myself to that.

Bottom line, bringing a child into the world should be an exciting and joyful time for women and their families. In light of the eternal truth that "children are a gift, the fruit of the womb is a reward". Mothers should feel secure and confident in their new role and not have to fear for their own life or their baby's life.

I thank the Chairwoman for scheduling today's hearing and I look forward to hearing from our witnesses.

I yield back.

[The statement of Mr. Walberg follows:]

Prepared Statement of Hon. Tim Walberg, Ranking Member, Subcommittee on Health, Employment, Labor, and Pensions

Today, we are here to discuss the critical issue of infant and maternal health. While women around the globe are dying less from childbirth, here, in the U.S., the rates have been climbing. Other countries with rising maternal mortality rates? Afghanistan, Lesotho, and Swaziland. For black women, the statistics are even more troubling. According to the World Health Organization, the maternal mortality rates for black women in the U.S. are the same for women in Mexico and Uzbekistan. This is unacceptable.

This issue, a matter of literal life and death for women, demands a serious and thoughtful response.

The exact causes of the United States' high maternal and infant mortality rates are unclear and varied. The HELP Subcommittee has jurisdiction over employment-related health benefits and the Employee Retirement Income Security Act, also known as ERISA. So, as we study the important issue before us today, and before this Committee considers the imposition of additional government mandates that could have unintended consequences on employers and employees alike, we should closely examine this problem through separate hearings about the larger issue and proposed legislative solutions. As we have learned from experience, one-size-fits-all government requirements, more often than not, compound the problem. That is why specific policies from this Committee and Congress must involve a thorough review of the current problem and a recognition that community, individual, and family engagement are also key components which need to be recognized and addressed.

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I know that both sides can agree that maternal and infant health is an issue worthy of attention, and it is my hope that we can hold additional legislative hearings on any proposed solutions and that any subsequent legislation can be considered in a bipartisan manner.

Bottom line, bringing a child into the world should be an exciting and joyful time for women and their families, in light of the eternal truth that 'children are a gift . . . the fruit of the womb is a reward.' Mothers should feel secure and confident in their new role, and not have to fear for their own life or their baby's life.

I thank the Chairwoman for scheduling today's hearing, and I look forward to hearing from our witnesses.

Chairwoman WILSON. Thank you so much, Mr. Walberg.

I now recognize Workforce Protection Subcommittee Chair Adams for an opening statement.

Ms. ADAMS. Thank you, Madam Chairwoman, and thank you to our witnesses for being here today.

As Co-Chair of the Black Maternal Health Caucus alongside Ms. Underwood, I am grateful for today's bipartisan opportunity to focus on our role in addressing America's maternal and infant health crisis. This crisis is devastating communities across the country, particularly Black and Native communities that experience far worse outcomes than their White counterparts. However, in some places in the country, such as in my home state of North Carolina, there are strategies in place that have been proven to work in reducing these disparities. It is up to us as lawmakers to make it easier for our caregivers to take what works and expand upon it.

Today our witnesses will help us understand and address the causes behind pregnancy—related mortality and morbidity that hit our communities every day.

As Chairwoman Wilson noted, expanding access to affordable health care and nutrition services is an important part of the solution. However, as women increasingly work later into their pregnancies and return to work shortly after the baby is born, we must also ensure that our workplaces support the health of mothers and infants. In this area Federal law falls woefully short.

For example, Federal law currently does not guarantee all new mothers the right to express breast milk. Workplace breastfeeding supports such as designated pumping breaks and private space are particularly critical for both maternal and infant health. Unfortunately, while employers are required to provide pumping breaks and break time for some workers, a gap in the law has caused millions of overtime-exempt employees to fall through the cracks. Further, even covered workers have limited avenues to ensure their employers provide pumping breaks and a private space. I think we can all agree that this is unacceptable. There is no question that our country is facing a maternal and infant health crisis. There is no question that our mothers and infants are suffering preventable tragedies that rarely occur in other developed nations. The only

question is whether we will come together and fulfill our responsibility to find solutions and to take action.

Again, I want to thank all of the witnesses for joining us today and, Madam Chair, I yield back.

[The statement of Ms. Adams follows:]

Prepared Statement of Hon. Alma S. Adams, Chairwoman, Subcommittee on Workforce Protections

Thank you, Chairwoman Wilson. As the co-chair of the Black Maternal Health Caucus alongside Ms. Underwood, I am grateful for today's bipartisan opportunity to focus on our role in addressing America's maternal and infant health crisis.

This crisis is devastating communities across the country, particularly Black and Native communities that experience far worse outcomes than their white counterparts. However, in some places in the country, such as in my home state of North Carolina, there are strategies in place that have been proven to work in reducing these disparities. It's up to us as lawmakers to make it easier for our caregivers to take what works and expand upon it.

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I think we can all agree that this is unacceptable. There is no question that our country is facing a maternal and infant health crisis. There is no question that our mothers and infants are suffering preventable tragedies that rarely occur in other developed nations. The only question is whether we will come together and fulfill our responsibility to find solutions and take action.

Thank you, again, to our witnesses for joining us today.

Chairwoman WILSON. I now recognize Workforce Protection's Ranking Member Walker for an opening statement.

Mr. WALKER. Thank you, Madam Chair.

Bringing a child into the world should be an exciting and joyful time for women and their families, not one clouded by fear and by worry. Unfortunately, infant and maternal mortality rates in the United States paint an abysmal picture. From 1990–2015 the U.S. mortality rate increased by 34 percent. To put that number into proper perspective, the global rate for maternal mortality decreased by 44 percent over that same time period. As for the United States infant mortality rates, they are declining, but remain 71 percent higher than the comparable country average.

Considering that the cause of these worsening and troublesome trends aren't clear, we must be cautious of implementing government mandates on employers that could end up potentially doing more harm than good. With that said, though, public policy has an important role to play in this issue, which is why there are protections under Federal law that safeguard mothers and their newborn babies' health.

For example, the Fair Labor Standards Act, the FLSA, requires employers to provide reasonable workplace accommodations and

break time for nursing mothers for 1 year after their child's birth. Women with children are the fastest growing segment of the workforce. According to the Department of Health and Human Services, 6 in every 10 new mothers are in the workforce. So the types of accommodations included in the FMLSA help our nation's workers and job creators succeed.

We agree that maternal and infant mortality trends are an important concern which deserves our attention. In the past Congress has been able to come together in a bipartisan manner to tackle serious policy challenges. For example, last year Congress passed H.R. 6, the SUPPORT for Patients and Communities Act, bipartisan legislation to address the opioid crisis, including mothers and infants affected by this terrible epidemic. Our hope is that we can continue this bipartisan work as we discuss solutions to address maternal and infant health here today.

In closing, hundreds of maternal deaths occur every year. These statistics are heartbreaking. As a Nation with some of the most advanced obstetrics and emergency care, we can and we should do better. But it is important that we legislate with a reasoned approach backed by a careful examination of the issue, which is why this hearing is a good starting point.

Again, thank you, Madam Chairwoman, for scheduling today's hearing. I look forward to a thoughtful discussion and hearing from all of our witnesses on how we can improve maternal and infant health conditions.

I yield back.

[The statement of Mr. Walker follows:]

Prepared Statement of Hon. Mark Walker, a Representative in Congress from the State of North Carolina

Thank you, Madame Chairwoman. Bringing a child into the world should be an exciting and joyful time for women and their families, not one clouded by fear and worry.

Unfortunately, infant and maternal mortality rates in the U.S. paint an abysmal picture. From 1990 to 2015, the U.S. maternal mortality rate increased by 34 percent. To put that number into perspective, the global rate for maternal mortality decreased by 44 percent over the same time. As for U.S. infant mortality rates, they are declining, but remain 71 percent higher than the comparable country average.

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care, we can and should do better. But it is important that we legislate with a reasoned approach backed by a careful examination of the issue, which is why this hearing is a good starting point.

Again, thank you, Madame Chairwoman for scheduling today's hearing. I look forward to a thoughtful discussion and hearing from our witnesses on how we can improve maternal and infant health outcomes.

Chairwoman WILSON. Thank you.

Without objection, all other members who wish to insert written statements into the record may do so by submitting them to the Committee Clerk electronically in Microsoft Word format by 5:00 p.m. on February 10, 2020.

I will now introduce our witnesses.

Stacey Stewart is the President and CEO of the March of Dimes. In this role Stewart heads the organization leading the fight for the health of all moms and babies.

Nikia Sankofa is the Executive Director of the United States Breastfeeding Committee, an independent nonprofit coalition of more than 100 influential professional, educational, and governmental organizations that share a common mission to drive collaborative efforts for policy and practices that create a landscape of breastfeeding support across the United States.

Dr. Joia Crear-Perry is the Founder and President of the National Birth Equity Collaborative and a board member of the Black Mamas Matter Alliance. She is a thought leader around racism as a root cause of health inequities.

Welcome to each of you powerful Black women.

We appreciate all of you for being here today and we look forward to your testimony.

Let me remind the witnesses, we have read your written statements and they will appear in full in the hearing record. Pursuant to Committee Cule 7(d) and committee practice, each of you is asked to limit your oral presentation to a 5-minute summary of your written statement.

Let me also remind the witnesses that pursuant to Title 18 of the U.S. Code, Section 1001, it is illegal to knowingly and willfully falsify any statement, representation, writing, document, or material fact presented to Congress, or otherwise conceal or cover up a material fact.

Before you begin your testimony please remember to press the button on the microphone in front of you so that it will turn on and the members can hear you. As you begin to speak the light in front of you will turn green. After 4 minutes the light will turn yellow to signal that you have 1 minute remaining. When the light turns red, your 5 minutes have expired and we ask that you please wrap it up.

We will let the entire panel make their presentations before we move to member questions. When answering a question, please remember to once again turn your microphone on.

I will now recognize Ms. Stacey Stewart. Welcome, Ms. Stewart.

TESTIMONY OF STACEY D. STEWART, PRESIDENT AND CEO, MARCH OF DIMES

Ms. STEWART. Thank you and good morning, Chairwoman Wilson and Chairwoman Adams, also Ranking Member Walberg and

Ranking Member Byrne, and members of the subcommittees. It is a pleasure for me to be here today, and thank you for inviting me to testify.

My name is Stacey Stewart. I am President and CEO of the March of Dimes. Every day at March of Dimes we lead the fight for the health of all moms and all babies. We began that fight more than 80 years ago as an organization dedicated to eradicating Polio in the United States, a goal that we achieved. We continue that fight today as we work to address some of the biggest threats to moms and babies, such as premature birth and maternal mortality, through research, through education, programs, and advocacy.

March of Dimes' mission is more important than ever before as our Nation, as many of you all have mentioned, is in the midst of a maternal and infant health crisis. Two babies die every hour in the United States and one woman dies every 12 hours as the result of complications from pregnancy and childbirth.

The most recent March of Dimes report card shows that the Nation's preterm birth rate rose for the fourth year in a row in 2018 and it revealed unacceptable disparities in outcomes for babies born in certain communities. Infants of color and those born in the southeastern United States are much more likely to be born too soon. In fact, the preterm birth rate among Black women is 49 percent higher than the rate among all other women.

The state of maternal health mirrors that of infants born too soon. Outcomes are getting worse and those worsening outcomes are driven by disparities. Each year approximately 700 women die from pregnancy complications, and for every maternal death another 70 women suffer life threatening health challenges. That is 50,000 women every year. These startling statistics make the U.S. one of the most dangerous developed places in the developed world in which to give birth.

The threat is especially acute for women of color. Black mothers of all ages are three times more likely to die from pregnancy-related causes and complications than their White peers. For Black and American Indian and Alaska Native women over the age of 30 rates of maternal death are 4 to 5 times higher.

We need your help to address this crisis by focusing on policies that will improve both maternal and infant health.

March of Dimes was pleased by the passage of the Preventing Maternal Deaths Act and the PREEMIE Reauthorization Act in late 2018. Both of these bills continue vital programs to collect enhanced data on the causes of maternal mortality and premature birth.

Fortunately, we don't have to wait for new data to take additional action. We know that the causes of this crisis are diverse. They can be traced issues in our health care system, including quality of care and implicit bias. They stem from factors in our homes, on our workplaces, in our communities.

There are additional steps you can take today to address this crisis. A full description of those steps can be found in my written testimony, but I will address policies most relevant to the subcommittees' jurisdictions now.

First, Congress should take all necessary steps to ensure that women have access to comprehensive and affordable health care

before, during, and after pregnancy and guaranteeing her newborn has the same from birth. The Patient Protection and Affordable Care Act codified a number of vital provisions, including protecting individuals with pre-existing conditions, guaranteeing coverage for maternity care, and ending annual and lifetime caps on coverage. Lawmakers must protect and build upon these protections.

The March of Dimes supports creating a new special enrollment period for pregnancy, as outlined in the Healthy MOM Act, to ensure all pregnant women have access to prenatal care. We also support efforts to protect families from surprise bills by simplifying the process for enrolling newborns in a family's health plan.

Congress can guarantee women and infants have access to both preventive care and treatment by strengthening the ACA's requirement that health plans cover preventive services for women and infants without cost sharing. Further, lawmakers should require health plans to cover a minimum number of free health care provider visits each year, as outlined in the Primary and Behavioral Health Care Access Act.

While health insurance and health care services are essential to healthy moms and babies, we cannot address this public health crisis by focusing exclusively on doctors' offices and hospitals. We have to address the barriers in our communities as well. We also applaud efforts to improve the WIC program. We strongly support reforms to ensure that every mom, no matter where she works, can continue to breastfeed if she chooses.

I look forward to expounding upon some of the proposals that we are talking about today, and thank you for having me.

[The statement of Ms. Stewart follows:]

TESTIMONY OF STACEY D. STEWART
PRESIDENT AND CEO, MARCH OF DIMES

BEFORE A JOINT HEARING OF
THE EDUCATION AND LABOR SUBCOMMITTEES ON
HEALTH, EMPLOYMENT, LABOR, AND PENSIONS
AND
WORKFORCE PROTECTIONS
"EXPECTING MORE: ADDRESSING AMERICA'S MATERNAL AND INFANT HEALTH CRISIS."

U.S. HOUSE OF REPRESENTATIVES
JANUARY 28, 2020



Good morning, Chairwoman Wilson, Chairwoman Adams, Ranking Member Walberg, Ranking Member Byrne and members of the Subcommittees. Thank you for the opportunity to testify at today's hearing, "Expecting More: Addressing America's Maternal and Infant Health Crisis."

I am Stacey Stewart, President and CEO of March of Dimes. Every day at March of Dimes we lead the fight for the health of all moms and babies. We began that fight more than 80 years ago as an organization dedicated to eradicating polio in the United States, a goal that we achieved. We continue that fight today as we work to address some of the biggest threats to moms and babies, such as premature birth and maternal mortality, through research, education, programs and advocacy.

March of Dimes' ongoing work to improve maternal and infant health is more important than ever as our nation is in the midst of a dire maternal and infant health crisis. Rates of preterm birth are increasing, the United States is one of the most dangerous places to give birth in the developed world, and there are unacceptable disparities in birth outcomes between women and infants of color and their white peers. Though you will hear me and my fellow panelists talk about threats to the health of moms and babies, it is critical to recognize that we are dealing with one crisis, not two. The health and well-being of mothers and infants are inextricably linked. By improving the health of women before, during and between pregnancies, we are guaranteeing improved outcomes for both them and their infants. I thank the Subcommittees for recognizing this is a single crisis and focusing on policies to improve both maternal and infant health in today's hearing.

OUR NATION IS IN THE MIDST OF A MATERNAL AND INFANT HEALTH CRISIS

Virtually every measure of the health of pregnant women, new mothers, and infants living in the United States is going in the wrong direction. In 2018, the nation's preterm birth rate rose for the fourth year in a row.[i] In many communities, infant mortality rates exceed those in developing nations.[ii] Approximately every 12 hours, a woman dies due to pregnancy-related complications.[iii]

This has led to an urgent crisis that demands a comprehensive response by policymakers at every level of government.

Premature Birth

Each year, March of Dimes releases its annual report card grading the United States, each of the states, the District of Columbia and Puerto Rico, on their progress toward improving maternal and infant health.[iv] Our most recent report card found that the nation's preterm birth rate rose for the fourth year in a row in 2018 – to 10.0 percent. The startling increase comes after nearly a decade of decline. As you might expect, the worsening national picture does not signal good news in individual states. Between 2017 and 2018, preterm birth rates worsened in 30 states. While we have one state, Oregon, earning an A-, we have six states and one territory earning a F. What do these statistics mean for the nation's families? They mean one in every 10 babies is born preterm, which can lead to life-long health problems and, in the most tragic cases, a baby's death.

These topline numbers tell only part of the story. Diving deeper into the data highlights an even starker reality for certain communities. With preterm birth rates as high as 14.2 percent (Mississippi), 13.0 percent (Louisiana), and 12.5 percent (Alabama), infants born in the southeastern United States are much more likely to be born early than those born in other parts of the country. Racial disparities exist across the United States. Hispanic, American Indian/Alaska Native, and Black babies are born premature at a rate surpassing their white peers. In fact, the preterm birth rate among Black women is 49 percent higher than the rate among all other women.

Maternal Health

The state of maternal health mirrors that of infants born too soon. Outcomes are getting worse and those worsening outcomes are driven by disparities. Each year, 700 women die from complications related to pregnancy.[v] For every maternal death, another 70 women suffer life-threatening health challenges. That's 50,000 women each year.[vi] While other countries have

reduced their maternal mortality rates since the 1990s, the U.S. maternal mortality rate continues to rise.[vii]

The threat of maternal mortality and morbidity is especially acute for women of color. Black mothers of all ages are three times more likely to die from pregnancy-related complications than their white peers.[viii] The rates of pregnancy-related death for Black and American Indian/Alaska Native women over the age of thirty are four to five times higher than their white peers.[ix] Black women are 27 percent more likely to experience severe pregnancy complications than white women.[x] These disparities cannot be explained by differences in age or education. According to the latest data from the Centers for Disease Control and Prevention (CDC), maternal mortality rates among Black women with a completed college education or higher was 1.6 times that of white women with less than a high school diploma.[xi]

Maternal mortality is also significantly higher in rural areas, where obstetrical providers may not be available,[xii] and delivery in rural hospitals is associated with higher rates of postpartum hemorrhage.[xiii] In October 2018, March of Dimes released a report showing that 5 million women live in "maternity care deserts," which are communities without a hospital offering obstetric services or providers.[xiv] Each year, 150,000 babies are born to mothers living in maternity care deserts.[xv]

A MULTIFACETED RESPONSE IS NECESSARY

The causes of our nation's maternal and infant health crisis are complex, and there is still much we do not know. That is why March of Dimes was pleased that Congress passed the *Preventing Maternal Deaths Act* (P.L. 115-344) and the *PREEMIE Reauthorization Act* (P.L. 115-328) in late 2018. Both bills continue vital programs at CDC to collect enhanced data on the causes of maternal mortality and premature birth, respectively, and translate that data into meaningful action to prevent future deaths.

Fortunately, we do not have to wait for new data to take action. We know that the causes of our nation's maternal and infant health crisis are diverse; they include physical health, mental health, social determinants, and much more. They can be traced back to issues in our health care system, including quality of care, systemic problems, and implicit bias. They stem from factors in our homes, our workplaces, and our communities. The evidence tells us there are additional steps policymakers can take **today** to protect the health of moms and their babies, including:

- Ensuring women have access to comprehensive and affordable health care before, during, and after pregnancy, and guaranteeing her newborn has the same from birth.
- Improving the health of both mom and baby by expanding innovative care models, such as group prenatal care.
- Enhancing data collection activities in communities and states to improve local and national data to drive action.
- Requiring health care provider training in implicit bias and cultural competency so all women receive the best possible care.
- Removing barriers to quality care in rural and other underserved communities.
- Enhancing protections in the workplace for pregnant women and new mothers.
- Expanding access to paid family leave.
- Strengthening existing public health and nutrition programs spreading evidence-based practices to improve maternal and infant health.

March of Dimes strongly supports policies that would advance the goals outlined above. Today, I will provide additional details on the policies most relevant to this Committee's jurisdiction.

PROTECTING AND ENHANCING HEALTH INSURANCE COVERAGE

The evidence is clear that access to health insurance is critical to improving the health of moms and their babies. Uninsured mothers and newborns are more likely to have poor birth outcomes than moms and babies with insurance coverage.[xvi] This difference in outcomes is

related, in part, to the care moms receive while pregnant. For instance, insurance coverage is associated with early initiation of prenatal care, which has been shown to reduce rates of low birthweight.[xvii]

But it is not just prenatal care that makes the difference. Improving the health of a mom before she becomes pregnant and in the postpartum period are essential to maternal and infant health. Chronic conditions that begin long before a woman becomes pregnant, such as high blood pressure, diabetes, heart disease and obesity, put women at higher risk of pregnancy complications and must be appropriately managed. More than one-third of pregnancy-related deaths between 2011 and 2016 are associated with cardiovascular conditions.[xviii] About one in nine women experience postpartum depression in the year after giving birth,[xix] and suicide is an increasing cause of maternal deaths in states around the country.

Maintaining Current Insurance Protections for Moms and New Babies

Given the importance of health coverage to mothers and newborns, it is imperative that policymakers maintain existing patient protections for all forms of health insurance. The *Patient Protection and Affordable Care Act of 2010* (ACA) contains a range of provisions to help ensure comprehensive, meaningful, and affordable coverage for women, infants and families. **Prohibiting discrimination against individuals with preexisting conditions** is essential for this population, as a chronic cardiovascular condition, a history of preterm birth, or even a past pregnancy, could have prevented a family from obtaining coverage prior to the ACA. Guaranteeing that health plans **cover 10 categories of essential health benefits (EHBs)** is also critical for moms and babies. EHBs ensure individuals have access to comprehensive benefits and services, including maternity care, well-woman and well-child preventive care, prescription drugs and mental health services. Prior to the ACA, only 13 percent of plans sold on the individual market offered maternity care.[xx] The ACA also includes protections to promote the affordability of insurance coverage. It **prohibits gender rating and annual or lifetime caps.** These provisions ensure that being a women is no longer a preexisting condition and that a complicated pregnancy or early birth will not bankrupt a family.

March of Dimes urges policymakers to ensure that these important consumer protections remain in place so that all women and infants can access the affordable, quality health care services they need.

Improve health insurance coverage for pregnant women and infants

The insurance reforms in the ACA should serve as the foundation for future reforms to improve access to quality health care for mothers and infants. March of Dimes supports the policies outlined below that will make coverage more accessible, comprehensive, and affordable.

Create a special enrollment period for pregnant women

Under current law, pregnant women can only enroll in a private health insurance during annual open enrollment periods. This can lead to situations where a woman who becomes pregnant while uninsured, or is covered by a grandfathered plan that does not cover maternity care, remains uninsured for all or a part of her pregnancy. Without maternity coverage, these women are more likely to forgo necessary prenatal care and face significant out-of-pocket costs for pregnancy complications.

March of Dimes strongly supports allowing newly pregnant women to enroll in coverage outside the designated open enrollment period. By creating a new special enrollment period (SEP) for pregnancy, policymakers will ensure that the 1.1 percent of women that report having no health insurance at the time of delivery can access critical care throughout the prenatal period.[xxi] New York and Connecticut have both recognized the importance of coverage for pregnant women by creating pregnancy SEPs for insurance plans sold in those states. It is time for Congress to do the same by passing the *Healthy Maternity and Obstetric Medicine (MOM) Act* (H.R. 2745/S. 1481). The legislation would create a SEP allowing newly pregnant women in every state to enroll in health insurance coverage through the Marketplaces, group health plans, and the Federal Employee Health Benefits system.

Ease barriers to enrollment for new babies

Pregnant women are not the only ones who would benefit from an improved enrollment experience. Many new families face unexpected medical bills and long phone calls with insurance companies as they attempt to add a new baby to their family's health plan. Enrolling a newborn in coverage is unnecessarily complicated, and can often be overlooked. This is especially true when things do not go according to plan. Moms recovering from a complicated delivery or new parents trading off shifts in the neonatal intensive care unit (NICU) can miss enrollment windows. That is why March of Dimes recommends simplifying the enrollment process for newborns to protect families from surprise medical bills after the birth of a child.

Guarantee access to important benefits

Of course, a health insurance plan is only as good as the services it covers. Congress should strengthen existing requirements for insurers to cover maternity care and certain preventive health benefits.

The ACA took the important step of requiring plans to offer dependent coverage up to age 26. However, further steps are needed to strengthen coverage in employer-sponsored plans. Since EHBs only apply in the individual and small group market, health plans sponsored by large employers are not required to provide coverage of maternity care for dependents. More than 4 million women are covered as dependents under their parents' policy, creating a loophole that potentially places women at risk of high out-of-pocket costs. This gap in coverage must be addressed to ensure all young women have access to quality maternity care.

The ACA also included important provisions that require health plans to provide essential preventive care services for women and infants without cost-sharing, promoting the utilization of these services to improve health and prevent disease. The Health Resources and Services Administration maintains a list of evidence-based, preventive care benefits for women, including comprehensive breastfeeding supports and counseling, screening for certain infectious diseases and dangerous health conditions, and tobacco cessation support, among

others. Ensuring that health insurance continues to provide this care without cost-sharing is crucial to healthy women, healthy pregnancies and healthy babies.

These preventive services are important, as are the appointments where they take place. That is why March of Dimes has endorsed *the Primary and Behavioral Health Care Access Act of 2020* (H.R. 5575), which requires insurance plans to cover three annual primary care visits and three annual outpatient mental health or outpatient substance use disorder treatment visits without cost-sharing. The reforms would ensure that new moms and their babies receive necessary care without worrying about financial barriers. These appointments are especially important for new moms and infants managing ongoing health issues stemming from pregnancy or a complicated labor and delivery.

Health insurance must also provide coverage when things do not go according to plan – whether that is a long stay in the NICU or surgery to correct a structural birth defect. Essential life-saving and life-improving care can cost a family hundreds of thousands of dollars if not covered by insurance plans. That is why March of Dimes supports the *Ensuring Lasting Smiles Act* (H.R. 1379/S. 560), which would require group and individual insurance plans to cover all medically necessary treatment for infants born with a congenital birth defect. The bill guarantees that families do not have to choose between their financial security and getting their babies and children the care they need.

IMPROVING MATERNAL AND INFANT HEALTH OUTSIDE THE CLINICAL SETTING

While access to health insurance and health care services is essential to promoting healthy pregnancies and healthy infants, we cannot address the nation's maternal and infant health crisis by focusing exclusively on doctor's offices and hospitals. We must also address barriers to health in our communities and our workplaces.

Protecting Pregnant Women in the Workplace

March of Dimes applauds this Committee and it members for promoting healthy pregnancies by taking steps to advance the *Pregnant Workers' Fairness Act* (H.R. 2694). Earlier this month, the Committee voted to send H.R. 2694 to the House Floor for a vote. That action was an important step toward ending workplace pregnancy discrimination that persists despite protections enacted by the *Pregnancy Discrimination Act of 1978* (P.L. 95–555). March of Dimes stands ready to work with you to enact this legislation before the end the 116th Congress.

It is essential, but not enough, to protect pregnant women in the workplace. We must also advance policies to ensure new moms are supported before and after returning to work.

Guaranteeing access to paid family leave

First, it is paramount that the United States joins the rest of the world in providing paid family leave to allow working moms and dads to care for a new child. The evidence clearly shows that paid family leave improves infant and maternal health outcomes. An international evaluation of paid leave policies showed that for every increase of 10 weeks of paid maternity leave, there was a 10 percent lower neonatal and infant mortality rate, even after controlling for other known risk factors for infant and child death.[xxii] Paid family leave benefits the economy, as well. A new study funded by March of Dimes' Center for Social Science Research found that states that have implemented paid family leave policies found that 20 percent fewer women leave their jobs in the first year after welcoming a child, and up to 50 percent fewer women leave the workforce after five years.[xxiii] Given the overwhelming benefits of paid leave for, March of Dimes strongly supports the *Family And Medical Insurance Leave (FAMILY) Act* (H.R. 1185/S. 463), which would create an affordable and self-sustaining national system to provide workers with up to 12 weeks of partial income through a family and medical leave insurance fund. March of Dimes is pleased that the House Ways and Means Committee is considering the FAMILY Act as we speak, and we will continue to advocate for its passage by both chambers of Congress.

Protecting new moms in the workplace

When a new mom returns to work after having a baby, she will need continued support in the workplace to ensure she can to continue to breastfeed her child if she chooses. Exclusive breastfeeding has a significant impact the health of the baby, as well as benefits for moms.[xxiv] However, returning to work can make continuing the breastfeeding relationship between mothers and their infants very difficult, especially if employers don't provide employees with adequate break time and an appropriate space to express breastmilk during the workday.

The ACA included provisions that required certain employers to provide break time and a place for most hourly wage-earning and some salaried employee to pump at work. The recently introduced *Providing Urgent Maternal Protections (PUMP) for Nursing Mothers Act* (H.R. 5592 /S. 3170) would extend those supports to the 9 million employees that were excluded from the ACA's protections.[xxv] These nurses, teachers, retail workers, and managers across a number of industries deserve the same protections as other working mothers. March of Dimes proudly endorses the *PUMP for Nursing Mothers Act* and appreciates the Subcommittees for including the bill in today's hearing.

Enhancing nutrition for moms and infants

March of Dimes applauds the Committee for its work to improve maternal and infant health through its support for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). WIC is responsible for reducing food insecurity, improving dietary intake, and creating better birth outcomes and health outcomes for millions of at-risk American families each year. A recent study added to the overwhelming evidence of the benefits of WIC by showing that WIC reduces infant mortality by one-third during the first year of life and lowers the risk of preterm birth for expectant mothers who participate.[xxvi] March of Dimes encourages the Committee to strengthen WIC. We are especially supportive of the *Community Access, Resources, and Education (CARE) for Families Act* (H.R. 3117), which would provide dedicated funds to local WIC clinics to enhance linkages to healthcare providers to improve the health of moms and babies served at those clinics.

CONCLUSION

March of Dimes again thanks the Subcommittees for turning their attention the nation's urgent maternal and infant health crisis. We continue to advocate fiercely for Congress to advance a comprehensive legislative package this year that will incorporate many of the policies above. We cannot wait to take action, because the state of maternal and child health in our nation is not fine. It's not fine that 700 new moms die each year because of pregnancy complications. It's not fine that babies of color die at rates far higher than white babies. It's not fine that families must make a choice between earning a paycheck and working in conditions that put the health of mom and baby in danger. But with the help of policymakers dedicated to making meaningful change, it can be. March of Dimes stands ready to help you achieve that change. I look forward to your questions.

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Chairwoman WILSON. Thank you, Ms. Stewart.
We will now recognize Ms. Nikia Sankofa.
Welcome.

TESTIMONY OF NIKIA SANKOFA, EXECUTIVE DIRECTOR, UNITED STATES BREASTFEEDING COMMITTEE

Ms. SANKOFA. Good morning, Chairwoman Wilson and Chairwoman Adams and Ranking Members Walberg and Walker.

Thank you for this opportunity to participate in today's hearing to discuss American's maternal and infant health crisis. It is an honor to share the insights I have gained from 2 decades of public health work at the community and national levels.

I am the Executive Director of the United States Breastfeeding Committee, an independent nonprofit coalition of more than 100 national, tribal, regional, state, and community organizations working together to drive policies and practices that create a landscape of breastfeeding support throughout the country.

Breastfeeding is a proven primary prevention strategy, building a foundation for lifelong health and wellness. Compared with formula fed children breastfed infants have a reduced risk of illness, infection, and infant death. Women who breastfeed their children have a reduced long-term risk of diabetes, cardiovascular disease, and certain cancers.

The evidence for the value of breastfeeding to children and women's health is scientific, robust, and continuously being reaffirmed by new research. Leading health organizations recommend exclusive breastfeeding for about 6 months followed by continued breastfeeding as complementary foods are introduced for at least the first year of life.

You might think that infant feeding decisions are a personal family matter, but we are all shaped by our circumstances. Lack of education in the prenatal period, maternity care practices that do not prioritize breastfeeding, returning home after birth unsure of where to go for support, and having lack of access to counseling and supplies, such as breast pumps, can compromise the early establishment of breastfeeding. And lack of support in the community and employment settings can stand in the way of continued breastfeeding.

Recent data show that 84 percent of infants were ever breastfeed, meaning that they initiated breastfeeding, indicating that most mothers in the United States want to breastfeed and start out doing so. But only a quarter are still breastfeeding exclusively at 6 months and 60 percent of mothers report that they did not breastfeed for as long as they intended.

Some of these barriers to breastfeeding exist outside of the mother's sphere of power or control and they disproportionately impact young women, those with low income, and women of color. This is reflected in significantly lower breastfeeding rates across all tracked indicators for these populations.

The key to supporting families and alleviating breastfeeding disparities is investing in upstream policy systems and environmental change solutions that deconstruct barriers and build environments where healthy choices, like sustained breastfeeding, can be the easy default option for most families.

Some well-known breastfeeding policy systems and environment change solutions include the Baby-Friendly Hospital Initiative, WIC's Breastfeeding Peer Counselor Program, and the 2010 Break Time for Nursing Mothers law, which was unanimously passed out of a bipartisan committee in recognition of the role that breastfeeding plays in infant and maternal health.

Even with these systemic solutions in place, we know more must be done. A simple and commonsense policy solution to addressing ongoing workplace barriers is within reach of this committee. The Providing Urgent Maternal Protections for Nursing Mothers Act, the PUMP Act, was introduced with bipartisan support for breastfeeding employees and it helps breastfeeding employees

while clarifying implementation processes for employers across the Nation.

Nearly one in four women of childbearing age, that is 9 million employees, are excluded from coverage under the current Break Time law, and as such they have no clear right to break time and a private space to pump breast milk. Although state legislation covers more than half of these employees, creating Federal laws ensures that employers from all sectors are considered and employees from all communities are supported under a national law that recognizes the important of breast milk in human and population health.

Without protections breastfeeding employees face serious health consequences, including risk of painful illness and infection, diminished milk supply, or inability to continue breastfeeding. According to a recent report from the University of California's Center for WorkLife Law, the consequences of this coverage gap also include harassment at work, reduced wages, and job loss, putting some new mothers in the position of risking their family's economic security by attempting to continue breastfeeding and working.

The PUMP for Nursing Mothers Act would strengthen the 2010 Break Time law by closing the coverage gap for women who are not currently covered, providing employers clarity on when pumping time must be paid and when it may be unpaid, and providing remedies for nursing mothers.

We know that the vast majority of people become parents during their lifetime and their needs and the needs of their infants are neither surprising nor difficult to meet if we plan appropriately.

Thank you for this opportunity.

[The statement of Ms. Sankofa follows:]

Written Statement of Nikia Sankofa
Executive Director of the U.S. Breastfeeding Committee
Before the Subcommittee on Health, Employment, Labor, and Pensions
and Subcommittee on Workforce Protections, United States House of Representatives
Joint Hearing: *Expecting More: Addressing America's Maternal and Infant Health Crisis*
January 28, 2020

Good morning. Thank you for the opportunity to participate in this hearing on improving maternal and infant health outcomes. Focusing mainly on reducing racial and ethnic health disparities, my public health work encompasses a broad range of functions from program design, monitoring and evaluation; data management and analysis; advocacy; and delivery of training and technical assistance. My educational background includes a Bachelor of Science in Chemistry, a Master of Public Affairs, and a Master of Public Health with a concentration in Women's Reproductive Health. I currently serve as Executive Director of the United States Breastfeeding Committee, a coalition of more than 100 organizations that support its mission to drive collaborative efforts for policy and practices that create a landscape of breastfeeding support across the United States.

It is an honor to bring to this committee the insights that I have gained from two decades of public health work at the community, state, and national levels.

In this testimony, I will discuss known barriers to breastfeeding success in the United States; how policies, systems, and environmental changes impact breastfeeding rates; and, a straightforward policy solution to dismantle obstacles to optimal breastfeeding that this committee can impact.

How Breastfeeding Impacts Health Outcomes

Breastfeeding is the biological norm for infant feeding. It is a proven primary prevention strategy, building a foundation for life-long health and wellness, and adapting over time to meet the changing needs of the growing child.[i] The evidence for the value of breastfeeding to children's and women's health is scientific, robust, and continually being reaffirmed by new research.

Breastfeeding is proven to reduce the risk of a range of illnesses and conditions for infants and mothers.[ii] Compared with formula-fed children, breastfed infants have a reduced risk of ear, skin, stomach, and respiratory infections; diarrhea; sudden infant death syndrome; and necrotizing enterocolitis. In the longer term, breastfed children have a reduced risk of obesity, type 1 and 2 diabetes, asthma, and childhood leukemia.[iii] Women who breastfed their children have a reduced long-term risk of type 2 diabetes, cardiovascular disease, and breast and ovarian cancers.[iv] For all these reasons, every major medical authority, including the Department of Health and Human Services, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, and World Health Organization recommends exclusive breastfeeding for the first six months of life followed by continued breastfeeding as complementary foods are introduced for at least the first year of life.

Barriers to Breastfeeding Success

Results from the CDC's most recent National Immunization Survey indicate that the vast majority of families choose to breastfeed in the United States.[v] However, U.S. policies, systems, and community and cultural environments inform a family's capacity to choose breastfeeding.[vi] While 83 percent of babies receive breast milk at birth, only 25 percent of U.S. infants are still exclusively breastfed at six months of age.[vii] Furthermore, a distressing 60 percent of mothers report that they did not breastfeed for as long as they intended.[viii] For many families, rather than being a matter of personal choice, infant feeding practice is informed by circumstance.

The principles of supply and demand guide human lactation. Regular removal of milk prompts the body to produce more milk. Establishing breastfeeding immediately after birth and maintaining milk production through frequent and regular feeding at the breast or pumping are essentials to building a successful breastfeeding relationship. Structural and environmental barriers can make it impossible for families to establish an adequate milk supply to sustain breastfeeding at medically recommended levels.[ix]

Health care policies and practices are critical determinants of breastfeeding outcomes. Prenatal and postpartum care and maternity care practices at delivering hospitals influence whether and how long babies are breastfed. As many as 75 percent of families do not have access to birthing facilities that implement evidence-based breastfeeding practices, and non-optimal maternity care practices in the context of breastfeeding can disrupt early feeding and undermine breastfeeding.

Too often, parents return home after birth unprepared and unsure of where to go for support. Many families depend on lactation support and counseling as well as supplies such as breast pumps to establish and sustain breastfeeding. Most breastfeeding-related problems, if identified and treated early, need not pose a threat to successful continuation. Unfortunately, many do not have access to the breastfeeding support they need and deserve to address questions and make informed decisions. Despite the importance of breastfeeding for population health, many health care providers receive limited training in lactation management.

In addition, a lack of support in community and employment settings can stand in the way of continued breastfeeding. The U.S. is one of only three countries that does not guarantee paid leave for new mothers.[x] Only 19 percent of the workforce has any paid family leave through an employer.[xi] The Family and Medical Leave Act provides for unpaid leave, but about 40 percent of the workforce is not eligible.[xii] Many parents return to work quickly after birth, before a strong breastfeeding relationship is established because they cannot afford to take unpaid leave or because they do not qualify for federal legal protections. More than half of mothers enter or return to the labor force before their children turn one year old,[xiii] with as many as one in four women returning within just two weeks of giving birth.[xiv]

When back at work or school, many people discover that they are unable to pump breast milk as frequently as necessary or they have no choice but to pump in an unsanitary or unsafe location, such as a bathroom or room without a locked door. Economically-marginalized women and non-white women are more likely to return to work earlier than their more affluent white counterparts, and they are more likely to have jobs that make it challenging to continue breastfeeding.[xv] Without needed accommodations, they are too often unable to produce enough milk for a caregiver to feed their child during separations and may not be able to maintain their milk supply.

Breastfeeding families throughout the United States are facing barriers that make it difficult or impossible to start or continue breastfeeding – but it does not have to be this way.

How Policies, Systems, and Environmental Changes Impact Breastfeeding Rates

The great majority of pregnant women and new parents want to breastfeed, but significant barriers in the community, health care, and employment settings can impede breastfeeding success.[xvi] Maternal, infant, and child health outcomes, including breastfeeding rates, are impacted by issues of intersectionality, including historical, cultural, social, economic, political, and psychosocial factors.[xvii] . Policy changes are necessary to influence upstream determinants of health and deconstruct barriers that inequitably compromise the capacity of many families to achieve their full health potential.

Inequities in the social determinants of health in communities of color and in economically marginalized communities contribute to stark inequities in breastfeeding initiation, duration, and exclusivity rates.[xviii] National Immunization Survey data for infants born in 2015 shows that the rate of exclusive breastfeeding at age 3 months was 53 percent among white infants but only 36 percent among black infants.[xix] Families of color are disproportionately impacted by structural barriers to breastfeeding and a lack of systemic interventions to protect, promote, and support breastfeeding in the communities where they work and live. For example, maternity care facilities in zip code areas with a higher population of black residents were significantly less likely than facilities in zip code areas with fewer black residents to follow recommended maternity care practices that support breastfeeding.[xx] Similarly, there are significant disparities in access to paid family leave among racial groups.[xxi]

The decisions of policymakers have a drastic impact on the overall American experience, including their health experience. Policy, systems, and environmental change strategies are designed to promote healthy behaviors by ensuring that healthy choices are the achievable and easy choices.[xxii] By ensuring that decisions are considered through a public health lens and informed by stakeholders across sectors and across the nation, we have the opportunity to create a landscape of breastfeeding support.

Public health initiatives, including legal and policy interventions and approaches designed to enable more infants to breastfeed, have the potential to markedly improve population health. We know that these strategies are effective.

In recent decades, attention and adaptation of the policies and infrastructure surrounding families has resulted in significant increases in breastfeeding rates. The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) serves roughly 7.3 million low-income mothers, babies, and young children at nutritional risk across the United States.[xxiii] In 2004, WIC launched their breastfeeding peer counselor program to help women initiate and continue breastfeeding by offering breastfeeding education, support, and role modeling.[xxiv] In 2007 only 2 percent of babies were born in hospitals that had optimal policies and practices that support mothers who want to breastfeed. Today, over 1 million babies—more than 26 percent of all births in 2018—occur in Baby-Friendly designated hospitals. In 2010, the first federal law to protect the right to lactation accommodations in the workplace was passed. Thanks to these policy changes, breastfeeding initiation has increased from 73.8 percent in 2007 to the current rate of 83.2 percent. Over that same time period, exclusive breastfeeding at 6 months has increased from 11.3 percent to 24.9 percent. These increases are astounding – but our work is not finished yet.

The vast majority of people become parents during their lifetime, and their needs are neither surprising nor difficult to meet if we plan appropriately. With this testimony, I hope to shed a light on the most urgent needs faced by today's breastfeeding families and highlight a simple, bipartisan policy opportunity within this committee's jurisdiction that can create a world of difference for breastfeeding families.

Many national initiatives are underway to alleviate these barriers, and you each have a critical role to play in ensuring that we continue to make progress toward national health objectives and improving the lives of families across the country. Together we can create laws and policies that can enable women to initiate and sustain breastfeeding successfully through the first year of life. The solutions are clear and cost-effective, and this committee has an essential role in making those solutions a reality so that for families, the healthiest choice is the easiest choice.

Policy Solutions to Eliminate Barriers to Breastfeeding Success

A simple and common-sense policy solution to address workplace barriers to breastfeeding is the Providing Urgent Maternal Protections (PUMP) for Nursing Mothers Act. Introduced with bipartisan support, the PUMP for Nursing Mothers Act would support breastfeeding employees across the nation by strengthening the existing Break Time for Nursing Mothers law.

The Break Time for Nursing Mothers law (Break Time law), passed in 2010, provides critical protections to ensure that employees have reasonable break time and a safe, private place to pump breast milk.[xxv] Unfortunately, the placement of the law within the section of the Fair Labor Standards Act that sets overtime resulted in 9 million women[xxvi] — nearly one in four women of childbearing age — being excluded from coverage and as such they have no clear right to break time and space to pump breast milk. Those left unprotected include teachers, software engineers, and many nurses, among others.

Thankfully, many of these employees are protected under state level legislation. More than half of all states have enacted legislation that impacts breastfeeding employees.[xxvii] For many of these states, the PUMP for Nursing Mothers Act would have little to no impact on employer requirements.

Without these protections, breastfeeding employees face serious health consequences, including risk of painful illness and infection, diminished milk supply, or inability to continue breastfeeding. According to a recent report from the University of California's Center for WorkLife Law, the consequences of this coverage gap also include harassment at work, reduced wages, and job loss, putting some new mothers in the position of risking their family's economic security by attempting to continue breastfeeding and working.[xxviii]

The PUMP for Nursing Mothers Act would strengthen the 2010 Break Time law by:

- *Closing the coverage gap.* The bill would protect the 9 million employees excluded from the 2010 Break Time law by extending the law's protections to cover salaried employees as well as other categories of employees currently exempted from protections.

- *Providing employers clarity on when pumping time must be paid and when it may be unpaid.* The bill leaves in place existing law protecting many salaried workers from having their pay docked, and it clarifies that employers must pay an hourly employee for any time spent pumping if the employee is also working, a common occurrence for many employees.

- *Providing remedies for nursing mothers.* The bill would ensure that nursing mothers have access to remedies that are available for other violations of the FLSA, bringing this law into alignment with other requirements that are familiar to employers.

No matter where they are or what they are doing, breastfeeding parents must feed their babies or express breast milk every few hours. This is necessary in order to maintain their milk supply, ensure there is adequate milk to meet their baby's nutritional needs, and avoid pain or serious infection. Breastfeeding mothers who return to work should not have to struggle to find time and space to express milk, risking their milk supply and thereby their ultimate breastfeeding success.

Businesses of all sizes and in every industry have found simple, cost-effective ways to meet the needs of their breastfeeding employees as well as their business. The Department of Health and Human Services (HHS) Office on Women's Health hosts the Supporting Nursing Moms at Work resource,[xxix] which provides a critical link between the need for workplace support for breastfeeding families and the need for implementation guidance for their employers. The online resource provides a user-friendly tool that employers can easily navigate to identify and implement industry-specific solutions to providing time and space accommodations. These examples are already helping employers and employees identify practical solutions that work for their industry and for their workspace so that they are in compliance with the Break Time for Nursing Mothers law.

The accommodations range widely. Fast food restaurants have different considerations than construction sites. The Break Time for Nursing Mothers provision is written with language that provides immense flexibility in recognition of these differences and does not require the construction of a permanent, dedicated lactation space. The PUMP for Nursing Mothers Act would maintain this flexibility.

What does this mean on a practical level? A breastfeeding employee must pump about as often as the baby usually eats. This means that generally speaking employees will need to pump their milk about every 3 hours every day during the workday. According to the HHS *Business Case for Breastfeeding* it usually takes around 15-20 minutes to pump breast milk, plus the time it takes to travel to the pumping space, set up and clean supplies, and store the pumped milk.[xxx]

Under the existing Break Time law, breaks do not need to be paid[xxxi] unless they are concurrent with paid breaks. If a nursing employee is not completely relieved from duty during a break to express breast milk, the time must be compensated as work time. Many employers allow workers the flexibility to come in early or stay late to make up for unpaid break time.

Providing staff coverage when employees are taking a pumping break can be handled in a variety of ways. In many businesses, workers cover for one another or the supervisor or manager may provide coverage when an employee needs to be away from the workstation. Some businesses employ designated floaters to provide coverage when an employee is taking a break or will adjust an employee's work schedule to accommodate her needs. All the same strategies that businesses use for any other type of break time, such as rest breaks, meal breaks, or medical breaks can be utilized to support breastfeeding employees.

In non-traditional work settings, creative solutions are making it possible for employees around the nation to continue breastfeeding after returning to work. Transportation employees are given a slightly different route that can accommodate lactation breaks, or sales employees are given a different but

equitable client list. Some employees may need different duties temporarily. For example, a bulletproof vest worn by some police officers may interfere with milk expression, and it may not be possible to find a private lactation space while on duty.

The existing Break Time law requires employers to provide a place to pump that is not a bathroom. It must be completely private so that no one can see inside the space and no one is able to enter the space while it is being used. To be functional, the pumping space simply needs to be furnished with seating and a flat surface such as a desk, small table, or shelf for the breast pump.[xxxiii]

In office buildings, many businesses use a small existing office, or use cubicle partitions to create a lactation space. Other businesses have converted closets and storage spaces to create permanent milk expression areas, with the only expenses being cleaning fees and the cost of seating and a flat surface. Health care facilities often use a patient or exam room and retail stores often use fitting rooms. Businesses in the same shopping mall or plaza may create a shared space that is available to employees in all of the businesses. In outdoor worksites, pop up tents or the cab of a construction vehicle are used to meet the needs of breastfeeding employees.

In many workplaces, there is no unused space. In that case, the employer could instead provide access to a space normally used for other things, like a manager's office or a storage area. Alternatively, if more than one breastfeeding employee will need the space, mothers can develop a room-use schedule or the employer can install privacy curtains or dividers so that the room can be used by more than one person at a time. To put it simply, if the space is available each time the breastfeeding employee needs it, the employer is meeting the requirements of the law. If there are no breastfeeding employees, the employer does not need to maintain a space.

Accommodating breastfeeding employees has not been the norm, but the tide is turning. The Society for Human Resources Management Employee Benefits Survey found that in 2009, only 25 percent of surveyed businesses had an onsite lactation room. In 2018, that number had nearly doubled to 49 percent.[xxxiv]

Implementation of the Break Time for Nursing Mothers law has shown that by working ahead of time to find solutions, the needs of businesses and breastfeeding employees can be easily anticipated and met. In fact, according to the HHS *Business Case for Breastfeeding,* employers that provide lactation support see an impressive return on investment (almost 3:1), including lower health care costs, absenteeism, and turnover, and improved morale, job satisfaction, and productivity.[xxxv]

If providing break time and a private, non-bathroom space is truly not possible, causing significant difficulty or expense, an employer with 50 or fewer employees may raise an undue hardship defense in the event of an investigation from the Department of Labor.

Despite the critical necessity of breastfeeding accommodations and the flexibility of the law's requirements, research shows that 40 percent of breastfeeding employees do not have access to both break time and a private non-bathroom space to pump during the workday.[xxxvi]

A significant gap that has surfaced is the lack of remedial measures related to the Break Time law. Little recourse is available for employees who are covered by the Break Time law to ensure they can use their rights. If an employer refuses to comply, a breastfeeding worker can file a complaint with the Department of Labor Wage and Hour Division, which will then begin an investigation. If the investigation

finds that an employees' rights were denied, the Wage and Hour Division (but not the employee) can go to court to obtain an order requiring the employer to comply.

Importantly, Section 7(r) of the FLSA does not specify any penalties if an employer is found to have violated the break time for nursing mothers requirements. This means that in most instances, an employee may only bring an action for unpaid minimum wages or unpaid overtime compensation and an additional equal amount in liquidated damages. According to the Request for Information on the Break Time for Nursing Mothers provision, which includes the Department of Labor's preliminary interpretations of the law, "Because employers are not required to compensate employees for break time to express breast milk, in most circumstances there will not be any unpaid minimum wage or overtime compensation associated with the failure to provide such breaks."[xxxvii]

The Center for WorkLife Law report, "EXPOSED: Discrimination Against Breastfeeding Workers" describes the practical implications. Nearly all legal claims that an employer failed to provide break time and space have been thrown out of court.[xxxviii] Since the passage of the Break Time law, only two claims have been allowed to proceed on the theory that the lactating employees in those cases suffered lost wages as a result of the break time violation. The report describes the case of an Emergency Medical Technician who was fired for requesting break time and space. The judge in that case stated that "While the Court is sympathetic to Plaintiff's argument that this renders [the Nursing Mothers law] ineffective, there is no support from the case law or DOL [Department of Labor]" to provide a remedy.[xl]

In the event that an employee is fired or discriminated against as a result of filing a complaint or cooperating in an investigation, they may file a retaliation complaint with the Wage and Hour Division or a private cause of action.[xli] In this extremely limited circumstance, an employee may be able to make the case for a meaningful monetary settlement.

Without a strong enforcement mechanism, employers do not fear the consequences of noncompliance. The PUMP for Nursing Mothers Act would ensure that remedies that are available for other violations of the FLSA are also available if an employer does not provide break time and a private space to ensure consistency of the law.

Over the past decade we have learned how to make breastfeeding and employment work, but the significant coverage gaps in the Break Time for Nursing Mothers law mean that workplace breastfeeding accommodation implementation is radically inconsistent. Employees of the same company and in the same building frequently do not have access to the same accommodations, and to figure out who must be accommodated can be complicated for businesses. The employees that fall between the cracks are left to choose between breastfeeding and their paycheck. That is why the PUMP for Nursing Mothers Act represents the next critical step toward bringing federal legislation into alignment with the needs of our nation's families and their employers.

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Chairwoman WILSON. Thank you, Ms. Sankofa.
We now recognize Dr. Joia Crear-Perry.
Welcome.

TESTIMONY OF JOIA CREAR-PERRY, MD, PRESIDENT, NATIONAL BIRTH EQUITY COLLABORATIVE

Dr. CREAR-PERRY. Thank you so much. Thank you, Chairwoman Wilson, Chairwoman Adams, Ranking Members Walberg and Byrne, as well as members of the House Committee on Education and Labor, for allowing me, Dr. Joia Crear-Perry, to provide testimony for this Expecting More: Addressing America's Maternal and

Infant Health Crisis hearing representing the National Birth Equity Collaborative and the Black Mama's Matter Alliance.

We can support improvements for all workers of reproductive age to grow their families with the appropriate wages, dignity, and protections they deserve. Women are integral to every industry in the U.S. Can they trust this body to support them through their pregnancy and return to the workforce? We can begin by shoring up the existing state investments for new mothers that are based upon evidence, like diversifying our workforce, scaling and deepening the ACOG Alliance for Innovation on Maternal Health, and building a community for respectful care, increasing our investment in the CDC-supported Perinatal Quality Collaboratives, mandating implicit bias and anti—racism training, and uplifting the leadership influence of the National Institutes of Health, Office of Research on Women's Health, Federal Divisions.

We can solidify these investments by heeding the recommendations of entities like us at the Black Mamas Matter Alliance.

As has been mentioned, the CDC defines pregnancy-related death as a death of a woman while pregnant or within 1 year of the end of pregnancy, regardless of outcome, duration, or site of the pregnancy, from any cause related to or aggravated by pregnancy and its management. Based on that definition, the CDC found in their surveillance 2,726 women died in the United States between 2011 and 2014, and of those 1,010, or 38 percent were Black. Based on that data and estimates of maternal mortality data from the CDC, a modest estimate of loss of preventable causes is about 1,000–1,500 Black mothers in the last decade. That is a caravan of coach buses each year. This is unacceptable.

Furthermore, over 60 percent of these deaths were preventable. As a Black woman from the Deep South who is an obstetrician and a mother, my strong desire to end this inequity is amplified every time I look into the faces of my daughter and my patients. The legacy of a hierarchy of human value based upon the color of our skin continues to cause differences in health outcomes, including maternal mortality. Racism is the risk factor, not my Black skin. There is not Black gene. Race is a social and political construct. Maternity mortality extends beyond the period of pregnancy and birth. Nine months of prenatal care cannot counter underlying social determinants of health inequities, in housing, political participation, transportation. Currently we do not have access to maternity care that is culturally congruent. Lack of workforce diversity and provider shortages are a direct consequence of policies created in halls like this that date back to the 1921 Sheppard-Towner Act, among others.

I am the founder of the National Birth Equity Collaborative and on the founding board of the Black Mamas Matter Alliance. The National Birth Equity Collaborative creates solutions that optimize Black maternal and infant health through training, policy and advocacy, research, and community centered collaboration. When working with large hospital systems as we currently do, health departments, and large legacy organizations to build a culture of reproductive justice, we have learned that Federal policy and investment is critical. As Black birthing people we have been devalued

for generations, and that devaluation shows up in your policy choices that you pick today.

The Black Mamas Matter Alliance serves as a national voice and coordinating entity for stakeholders advancing maternal health, rights, and justice and intentionally centers Black women's leadership. BMMA has a network of organizations with reach and relationships and capacity that you could support for an intergenerational movement.

Ultimately, what Black women in the United States need is accountability. We need to know that our lives are valued. This accountability may be complicated, by government still has an obligation to act. Racism, classism, and gender oppression are killing us from rural to urban America. This is not about intentions. Lack of action is unintentionally killing us and it is a human rights imperative.

This hearing that calls for us to expect more is an opportunity for esteemed members of this Education and Labor Committee to look deeply at all the ways policies around our social determinants of health are causing maternal morbidity and mortality. We must be willing to continue to name this problem directly.

Yes, Black Mamas Matter.

[The statement of Dr. Crear-Perry follows:]

JAN 28, 2020

WRITTEN TESTIMONY

OF

JOIA CREAR - PERRY, MD

FOUNDER and PRESIDENT

NATIONAL BIRTH EQUITY COLLABORATIVE

BOARD MEMBER

BLACK MAMAS MATTER ALLIANCE

THE

SUBCOMMITTEE ON HEALTH, EMPLOYMENT, LABOR AND PENSIONS AND SUBCOMMITTEE ON WORKFORCE PROTECTIONS

COMMITTEE ON EDUCATION AND LABOR

U.S. HOUSE OF REPRESENTATIVES

“EXPECTING MORE: ADDRESSING AMERICA’S MATERNAL AND INFANT CRISIS”

10:00 a.m., TUESDAY, JANUARY 28, 2020

Testimony of Dr. Joia Crear-Perry

Founder National Birth Equity Collaborative

"Expecting More: Addressing America's Maternal and Infant Health Crisis"

U.S. House Committee on Education and Labor

Thank you Chairwoman Wilson and Chairwoman Adams and Ranking Members Walberg and Byrne as well as members of the House Committee on Education and Labor for allowing me, Dr. Joia Crear- Perry, to provide testimony for this Expecting More: Addressing America's Maternal and Infant Health Crisis hearing representing the National Birth Equity Collaborative and the Black Mamas Matter Alliance.

We can support improvements for all workers of reproductive age to grow their families with the appropriate wages, dignity and protections they deserve. Women are integral to every industry in the U.S. Can they trust this body to support them through their pregnancy and return to the workforce? We can begin by shoring up the existing state investments for new mothers that are evidence based; Diversifying our workforce, scaling and deepening the ACOG Alliance for Innovation on Maternal Health for Respectful Care, increasing our investment in CDC supported Perinatal Quality Collaboratives, mandating Implicit Bias and Anti Racism Trainings, and uplifting the leadership influence of National Institutes of Health Office of Research on Women's Health on federal divisions to address racial inequities in maternal health. We can solidify these investments by heeding the recommendations of entities like us at the Black Mamas Matter Alliance.

As you may be aware, the United States is the only developed

country in the world where maternal mortality is on the rise. Further, Black women in the U.S. die at 3 to 4 times the rate of their white counterparts.[1] Despite clear evidence of this inequity, policymakers, and as a consequence, our US government had not, until now, addressed this urgent public health and human rights issue. The Centers for Disease Control defines Pregnancy Related death as the death of a woman while pregnant or within one year of the end of a pregnancy – regardless of outcome, duration or site of the pregnancy – from any cause related to or aggravated by pregnancy or its management. Based on that definition, the CDC found in their surveillance, 2,726 women died in the United States between 2011 and 2014 and of those 1,010 or 38% were Black. Based on that definition and estimates of mortality data from the CDC, a modest estimate of loss to preventable causes is 1000-1500 Black mothers in the last decade. That's a caravan of Coach buses each year. This is unacceptable.[2] [3] Furthermore, over 60 percent of those deaths were of preventable causes.[4] A recent study of pregnancy related deaths in my home state of Louisiana found that Black women died at more than four times the rate of White women. Among the deaths of Black women in Louisiana, almost 60% of them were potentially preventable, while only 9% of the deaths of White women were deemed preventable.[5] As a Black woman from the Deep South, who is an obstetrician and a mother, my strong desire to end this inequity

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[1] Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: http://dx.doi.org/10.15585/mmwr.mm6835a3

[2] Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: http://dx.doi.org/10.15585/mmwr.mm6835a3external icon.

[3] Montagne, R. (2018) NPR. For Every Woman Who Dies In Childbirth In The U.S., 70 More Come Close. https://www.npr.org/2018/05/10/607782992/for-every-woman-who-dies-in-childbirth-in-the-u-s-70-more-come-close

[4] Davis NL, Smoots AN, Goodman DA. Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2019.

[5] Mehta PK et al. Racial inequities in preventable pregnancy-related deaths in Louisiana, 2011-2016. Obstet Gynecol 2019;135:276-283. Retrieved from: https://journals.lww.com/greenjournal/Abstract/2020/02000/Racial_Inequities_in_Preventable_Pregnancy_Related.6.aspx

is amplified every time I look into the faces of my daughter and patients.

As a Black mother, I cannot buy or educate my way out of dying at 3 to 4 times the rate of a white mother in the United States. The inequity in maternal mortality rates persists regardless of our income or education status.[6] A White woman with less than a high school education has a better chance to live in childbirth than a Black woman with a college degree. Health data for Indigenous and Native American populations is less reported, yet frequently mirrors this inequity.[7] The legacy of a hierarchy of human value based on the color of our skin continues to cause differences in health outcomes, including maternal mortality. Racism is the risk factor – not Black skin, not Race. Race is a social and political construct.

Maternal mortality extends beyond the period of pregnancy or birth. Nine months of prenatal care cannot counter underlying social determinants of health inequities in housing, political participation, transportation, education, food, environmental conditions, and economic security; all of which have racism, classism, and gender oppression as their root causes. We have data that shows that a Black woman who initiates prenatal care in the first trimester has a worse outcome in birth than a White woman with late or no prenatal care. Currently we do not have access to Maternity care that is culturally congruent. Lack of workforce diversity and provider shortages are a direct consequence of policies created in these halls that date back to the 1921 Sheppard-Towner Act among others. This Act provided matching funds to states for prenatal and children's health centers. Although the act had positive effects—like increasing funds to health care—it discouraged the practice of midwifery, particularly Black

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[6] Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: http://dx.doi.org/10.15585/mmwr.mm6835a3.

[7] Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: http://dx.doi.org/10.15585/mmwr.mm6835a3

midwifery, and portrayed midwives as too uneducated and unclean to direct births. All midwives soon saw a decrease in activity, but Black midwives were especially targeted by Sheppard-Towner. Consequently, they lost their positions as birth leaders and became "birth assistants."

Good maternal health outcomes depend upon implementation of all sexual and reproductive rights, from comprehensive sexual education to access to all forms of birth control and safety from Intimate Partner Violence. We know that Medicaid Expansion[8], protecting the ACA, Domestic Violence prevention and mental health parity laws are critical to ensuring that Maternal Mortality rates improve across our great nation. We have data that shows that this investment in states, such as my own great state of Louisiana through Medicaid Expansion, saves money and lives. Even if women are insured, coverage of sexual and reproductive health services is too often not comprehensive. Receiving the full range of reproductive options ensures safe healthy births for moms and babies.

There are many policy solutions available to improve the economic and workplace gender discrimination that negatively impact birth outcomes. Two weeks after delivery, the uterus is shrinking to its normal size, there is frequent bleeding and the organs are finding their original placement. Nearly 1 in 4 mothers are returning to work earlier than that to make up for lost wages at jobs that do not guarantee time to pump breastmilk, nor provide a storage cooler to ensure it is safe for ingestion.[9] Breastfeeding is protective for both the mother and the infant's mental and emotional health.[10] Most

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[8] Searing A, Ross C D. Medicaid Expansion Fills Gaps in Maternal Health Coverage Leading to Healthier Mothers and Babies. Georgetown Center for Children and Families. 2019. Retrieved from: https://ccf.georgetown.edu/wp-content/uploads/2019/05/Maternal-Health-3a.pdf

[9] Family and Medical Leave in 2012: Detailed Results Appendix. Abt Associates. 2014. https://www.dol.gov/sites/dolgov/files/OASP/legacy/files/FMLA-Detailed-Results-Appendix.pdf

[10] Breastfeeding in underserved women: increasing initiation and continuation of breastfeeding. Committee Opinion No. 570. American College of Obstetricians and Gynecologists. Obstet Gynecol 2013;122:423–8.

workers do not have access to paid leave to take care of an infant, an elder, a sick family member, or their own needs- like weekly high risk prenatal appointments.[11] Many workers, like in my own city of New Orleans, work in industries like hospitality. They are cook the food and flip the beds in the hotels we sleep in as tourists, without access to any time off to attend a High Risk Prenatal visit. If they must make a choice between the $7.25/hour to feed their families or sitting at a High Risk Prenatal visit, more often than not feeding their family is the priority.

Black women with family caregiving responsibilities are estimated to spend 41% of their annual income on expenses related to caregiving, in contrast, White caregivers spend approx. 14% of annual income on caregiving expenses.[12] Caregiving includes childcare costs, which are further exacerbate the income inequality experienced by families of color. We need protections and supports in paid leave and childcare to bolster any advancements made in healthcare or payment systems for maternal health care.

Private insurance and payment systems are responsible for maternal health outcomes, as well. In 2018, almost 70% of women ages 19-64 were covered by private health insurance.[13] High cost sharing and deductibles for maternity care,[14] even surprise bills from labor & delivery, cause gaps in coverage for women who cannot sustain spiking prices. The short term health plans offered on some state exchanges do not cover maternity care, which many find out after

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[11] Geizan RVW. Paid leave in private industry over the last 20 years. Bureau of Labor Statistics. 2013. https://www.bls.gov/opub/btn/volume-2/paid-leave-in-private-industry-over-the-past-20-years.htm

[12] Rainville C, Skufca L, and Mehegan L. Family caregiving and out-of-pocket costs: 2016 report. AARP. Retrieved from: https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf

[13] Women's health insurance coverage. Kaiser Family Foundation. 2020. Retrieved from: https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/#footnote-446031-1

[14] Moniz M et al. Out-of-pocket spending for maternity care among women with employer-based insurance 2008-15. Health Affairs. 2020. https://doi.org/10.1377/hlthaff.2019.00296

they read a positive pregnancy test. Families scramble to take care of necessary health care expenses, shouldering the economic burden that is exasperated by the lack of workplace protections. This is reminiscent of the inadequate insurance coverage for maternity care that dominated the market before the passage of the ACA. Let's, at a minimum, maintain this progress.

Closures of hospitals and maternity units create barriers to services and information.[15] This lack of a safety net for poor and rural Americans produces gaps in access along the reproductive life span.This includes closures of rural hospitals across the United States with those in majority Black rural areas closing first and most often. All of us are impacted when we make choices to defund Critical Access facilities and disinvest in communities that we deem not economically viable. Research indicates that women living in rural communities are more likely to face maternal mortality and severe maternal morbidity, and I have seen this firsthand.[16] As someone who grew up in rural America, my best friend had her baby in the car on the way to the hospital that was an hour away. That child has severe cerebral palsy. What is the value of these often forgotten communities and families? What are we saying about how we value them in our policy and funding priorities?

I am the founder of the National Birth Equity Collaborative and on the Founding Board of the Black Mamas Matter Alliance. The National Birth Equity Collaborative creates solutions that optimize Black maternal and infant health through training, policy advocacy, research, community centered collaboration. When working with large hospital systems, health departments and large legacy organizations to build a culture of Reproductive Justice, we have learned that federal policy and investment is critical. As Black

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[15] Peiyin H et al. Why are obstetric units in rural hospitals closing their doors? Health Serv Res. 2016 Aug; 51(4): 1546–1560.

[16] Kozhimannil KB, et al. Rural-Urban Differences In Severe Maternal Morbidity And Mortality In The US, 2007–15. Health Affairs 2019. Retrieved from: https://doi.org/10.1377/hlthaff.2019.00805

birthing people, we have been devalued for generations and that devaluation shows up in your policy choices. The Black Mamas Matter Alliance serves as a national voice and coordinating entity for stakeholders advancing maternal health, rights, and justice, and intentionally centers Black women's leadership. BMMA has a network of organizations with the reach, relationships and capacity to support an intergenerational movement. BMMA organizes around four core strategies which aim to 1) advance policy that addresses black maternal health inequity 2) cultivate innovative research methods, 3) enhance holistic and comprehensive approaches to the care of black mamas, and 4) shift culture of the narratives of black motherhood by amplifying black women's voices.

While maternal mortality in the U.S. is on the rise, data reflects that severe maternal morbidity is 100 times more common, impacting even more women and families.[17] To acknowledge women experiencing a severe maternal morbidity is to recognize that there are women suffering, at times, life-long consequences and medical complications as a result of pregnancy and childbirth. Medicare is the main driver of healthcare spending in the United States. Private Insurers look to what Medicare covers, which could be services such as Doula/Community Birth Workers, equity for Midwifery pay, multiple postpartum visits, behavioral health, when they are making economic decisions about how they will provide Employer based and Market based insurance coverage. Ultimately, what Black women in the U.S. need is accountability. We need to know that our lives are valued. This accountability may be complicated, but government still has an obligation to act. Racism, classism and gender oppression are killing all of us, from rural to urban America. This is not about intentions. Lack of action is "unintentionally"

[17] Severe Maternal Morbidity in the United States. Centers for Disease Control and Prevention. 2017. Retrieved from: https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html

killing us. It is a human rights imperative. This Hearing that calls for us to expect more, is an opportunity for the esteemed members of the Education and Labor Committee to look deeply at all of the ways the policies around our social determinants of health are causing Maternal Morbidity and Mortality .We must be willing to continue to name the problem directly. Racism is the risk factor that we must end. The Education and Labor Committee has taken a tremendous step forward in showing that we do recognize…Yes, Black Mamas Matter.

Chairwoman WILSON. Thank you, Dr. Crear-Perry.

Under Committee Rule 8(a) we will now question witnesses under the 5-minute rule.

I will now yield myself 5 minutes.

Dr. Crear-Perry, in your testimony you discuss the history of the Sheppard-Towner Act of 1921 and the impact it had on midwifery, and Black midwifery in particular. How many Black midwives are in practice and what policies do you think Congress could pursue to increase the number of Black midwives?

Dr. CREAR-PERRY. Well, we currently know that less than 5 percent of midwives in practice are Black and we also know that there is a shortage of midwifery in general in this country. When that

Act was enacted we were still operating in a belief that people of color and Black people were not fully capable of providing the care that everyone needs. And so we did things like that were harmful and didn't value the women who had been birthing America for generations.

So there is an opportunity for us to say well what is it that people and patients want. When we interview women, they really want less intervention, they want a midwife, they want someone who looks like them, who understands them. So an opportunity through Congress is to increase the workforce development, have nursing programs at HBCUs, like my own hometown of Grambling, to ensure that we have access to midwifery programs, because that is a direct pipeline. There are nursing schools at a lot of the HBCUs that do not have access to midwifery programs as well.

Chairwoman WILSON. Thank you.

In your testimony you discuss some of the history of racism within the field of obstetrics and gynecology. Today, we know that when Black women seek medical treatment they receive a lower quality of care than their White counterparts. Can you say more about the role of Dr. J. Marion Sims in this history of OB/GYN?

Dr. CREAR-PERRY. Yes, thank you so much.

So as you may know, Dr. J. Marion Sims traveled across the United States with three Black women who were enslaved. Their names were Lucy, Betsey, and Anarcha. I would like to uplift their names because they are human beings who existed, who we don't even honor and they don't have statues. We have statues and honors for J. Marion Sims. We name—if you are an OB/GYN and you reach for a retractor, you are asking for a Sims retractor. That name comes from a man who traveled around the country doing experiments on women without any anesthesia and then he wrote, based upon the fact that these Black women could handle these surgeries with anesthesia, that we clearly did not feel pain the same way that White women did. And that believe still pervades today. There are studies that show, from prestigious universities in the United States, that medical students still believe that Black people do not feel pain the same way. As if melanin has something to do with your pain receptors.

So it is important for us to really think about all the ways that racism is embedded in how we created obstetrics and gynecology, how we decimated midwifery, and how we still provide care today and how we do not acknowledge those truths. We are not taught even about J. Marion Sims when you are training in medical school or residency. So you don't even have an understanding of the retractor that you are asking for and how it was used and created on the bodies of people who were not valued.

Chairwoman WILSON. Okay, thank you.

About 1 in 33 children in the United States is born with a congenital anomaly. Some of these conditions, such as a cleft palate, can have serious impact on a child's ability to breathe and to speak.

Ms. Stewart, does March of Dimes support legislation such as Ensuring Lasting Smiles Act that would close this gap in coverage for these children?

Ms. STEWART. Thank you, Chairwoman.

Yes, the Ensuring Lasting Smiles Act is Federal legislation that would do some very important things.

First of all, it would ensure that all private group and individual health plans cover medically necessary services, including needed dental procedures as a result of congenital anomalies. And, as you mentioned, about 4 percent of children in the U.S. are born with these kinds of anomalies or birth defects. And of course the March of Dimes in our history has been very dedicated to addressing the issues of birth defects among children.

But the issue is that while most private health plans do provide coverage for surgical treatment of many of these anomalies and there are many states that actually require insurers to provide coverage for health services related to some of these birth defects, we still hear that there are too many health plans that often deny claims and appeals for oral or dental related procedures, like orthodontia or dental implants and other procedures. And what this means for these families is that they are often left to have to figure out how to pay for these services on their own. And some of those expenses can be extraordinary and often devastating financially to many of these families.

So we support the Ensuring Lasting Smiles Act along with over 30 other organizations because we think that when babies are born, due to no fault of their own or their families, with these kind of birth defects, they deserve and need the treatment, often these dental surgeries to make sure that not only can they really thrive as kids, but they can actually function as normal human beings, because some of these kinds of birth defects affect their ability to breathe, their ability to eat. They are more than just cosmetic surgeries, they are actually medically necessary, and medically indicated surgeries. So we are in strong support of the Ensuring Lasting Smiles Act because we believe that it will provide the support that is needed to so many of these families.

Some of these families are even here today, like the Abbott family from Wisconsin I just got a chance to meet, and families that have been really impacted by some of these issues. And without some of the support from the Ensuring Lasting Smiles Act we would leave too many families too vulnerable—

Chairwoman WILSON. Thank you.

Ms. STEWART.—and without the care that the need.

Chairwoman WILSON. Thank you very much.

I ask unanimous consent to enter into the record letters of support for this legislation.

I now recognize member Walberg, my Ranking Member for his round of questions.

Mr. WALBERG. Thank you, Madam Chairwoman, and thanks to the panel for being here today and taking the effort to join us this morning.

Ms. Stewart, last Congress I was proud to serve as member of the Energy and Commerce Committee as we passed a bipartisan bill, H.R. 1318, the Preventing Maternal Deaths Act, which reauthorized funding for the Centers for Disease Control and Prevention programs that support state and local maternal mortality surveillance and prevention programs, added additional funding for state governments to establish maternal mortality review commis-

sions. H.R. 1318 was signed into law by President Trump in December 2018. These state commissions worked to collect, to track, analyze, and report data on maternal and infant outcomes in states that have established these commissions.

How has the increased availability of data impacted maternal safety and quality improvement initiatives?

Ms. STEWART. Thank you.

Well, one of the things that is really important as we address the maternal and infant health crisis is being able to collect good data, good, reliable data across the country. And thank you for your support for the Preventing Maternal Deaths Act, because it did provide the impetus for every state to be able to establish what we call a maternal mortality review committee. We now have every state, with the exception of three, that have established these MMRCs. And what they are doing is actually going collecting the data. The underlying data is really important to understand the cause of death, why a mother may have died as a result, and tie it back to obviously the fact that she may have just had a baby or any of the causes due to pregnancy and childbirth.

These state-based committees are full of experts who really analyze this data and then help design recommendations or interventions to prevent further deaths from happening. So before this, we didn't have this kind of data collection effort. Now that we do, we are able to look more deeply at the underlying causes of maternal mortality and morbidity and design at a federal level or at a state level the kinds of interventions that will hopefully prevent these kinds of deaths from happening in the future. We would not be able to do this work and accelerate our interventions and our successes with this crisis if we didn't have more robust data collection.

Mr. WALBERG. It will certainly take some time for that to work in, but we are seeing benefits already?

Ms. STEWART. We are starting to see benefits. We still have three states that need to establish MMRCs and then we need to start collecting the data and reporting it up.

Mr. WALBERG. What are those states?

Ms. STEWART. South Dakota, North Dakota, and Wyoming, as I understand it.

Mr. WALBERG. Okay. Dr. Crear-Perry, high-risk pregnancies can pose significant challenges to all women and to health providers. I am a grandfather and when I am asked how many grandkids I have, I say one in heaven and five on the ground. My first two were twin boys born at 24 weeks, 1.12 ounces, 12 inches long. John Timothy is in heaven waiting, but thanks to the wonderful care that they received in Northwestern University Hospital on the north side of Chicago, Mike is now 13 and almost 6 feet tall, healthy, and going strong. But my daughter-in-law also was part of that process, and thank god she was given great care and pulled through.

So it is an important issue that we are talking about today. Some hospitals have successfully implemented standard protocols to address common high-risk scenarios. In looking at labor and delivery issues, hemorrhaging, high blood pressure, et cetera, how can these protocols help increase quality and decrease maternal mortality rates?

Dr. CREAR-PERRY. I had a one pounder myself. He is now 23 years old. He was supposed to come with me this morning, but he played video games too late last night, so he is not here with me. So I appreciate that.

Mr. WALBERG. So he is normal?

Dr. CREAR-PERRY. Exactly. So I am making him watch it on YouTube.

No, so it is important of course that the way that those tools work is we can have standards for hospitals. So, for example, the Joint Commission just passed—who accredits hospitals—asked the hospitals—they have about a year to get it together to report on hemorrhage and how they are using the bundles. And so we have seen improvements. In fact, the State of California saw a large decrease in the number of deaths after really implementing the use of those hemorrhage bundles and hypertension. And what they found, though, is that there still was bias around who was implementing the bundles. So now we are going back and we are saying how can we do this in a more equitable way and how can we do things like work on our implicit biases.

But it is important to have those tools so that you have a standard of how you are supposed to take care of patients.

Mr. WALBERG. Okay. I appreciate that.

In the very limited time here, Ms. Stewart, we talked about the United States and its problem. As U.S. maternal mortality rates continue to increase, are other countries experiencing similar increases and are we learning something from that as well?

Ms. STEWART. Well, we are sort of unique in that we are one of the few, if any, of the largest industrialized countries in the world with increasing maternal mortality rates. I think it was mentioned earlier that we kind of stand alone in that respect.

I do think there are things that we learned from other countries where the rates have been declining, where you see a range of other supportive policies to make sure that women are provided the support that they need. In the UK, for example, there are lots of supports that women are given through midwifery care and through other kinds of home visiting programs that actually are providing a lot of support to women during pregnancy and even postpartum. Our country lacks in terms of the ability to expand these kinds of policies to many women and that leaves many women falling through the cracks.

We also know a couple of things. One is that we will not solve this issue just by looking at the 9 months of pregnancy. We have to look at women before they are pregnant, during pregnancy, and after pregnancy. We also have to make sure that we look at health care and health and wellness for women. It is not just something that happens in the doctor's office because so many of the issues that impact a woman and her health and the baby's health have to do so much with their environment and what we call the social determinants of health, how they live their day to day lives. And until we get a full handle on policies that address the totality of how women live in this country, we won't be able to address this issue in the way we need.

Mr. WALBERG. Thank you. I yield back.

Chairwoman WILSON. Thank you. Thank you, Ranking Member Walberg.

I remind my colleagues that pursuant to committee practice materials for submission for the hearing record must be submitted to the Committee Clerk within 14 days following the last day of the hearing, preferably in Microsoft.

And now we will hear from our members. Dr. Adams, who has been on the forefront of this issue here in Congress, along with Nurse Underwood. I commend them.

Now, Dr. Adams.

Ms. ADAMS. Thank you, Madam Chair.

Dr. Crear-Perry, thank you for highlighting the importance of training providers as a strategy to reduce the racial disparities that we are seeing in maternal and infant health outcomes. And that is why I introduced the Maternal CARE Act, which would create implicit bias training grants.

In your experience working with physicians and other health care providers, how common is implicit bias training and what kind of gaps do you see in the training of health care providers?

Dr. CREAR-PERRY. So right now it keeps me very busy doing implicit bias training, and we just did one in Kaiser in Atlanta. We trained their entire maternal and child health division. So that is everybody from the people who answer the phone to the actual high-risk OB/GYNs.

So there is an opportunity we have right now to really build up on these trainings. My organization is one of several that do these trainings. I know the March of Dimes has created some work around that as well.

And the importance is that we need to understand our own biases in health care and how we were taught those things. And biases are not—they are coded in us, we can change it. We don't have to believe that Black people are broken, we don't have to believe that women can't do things. Those are things that we have been taught, and so they are part of our implicit biases now. But we can change that.

Ms. ADAMS. Thank you.

My home state of North Carolina has a program called Pregnancy Care Management and provides needs assessments, coordination of care, and other supports for eligible women with at-risk pregnancies. The program has been cited as a factor in—in halving the Black maternal death rate in North Carolina. Why is coordination of care and supportive services particularly effective for Black mothers? And what can Congress do to support these types of programs?

Dr. CREAR-PERRY. I have the honor of working with Dr. Menard and others at UNC around that work, the Pregnancy Medical Home work, and this idea that you can have coordination. Because as was mentioned by Ms. Stewart, we are losing people in the gaps. They don't have access to the coordination around breastfeeding or if they need transportation or housing. So this coordinated care model, which was I think spun out through Medicaid, allows for you to then also have coordination with other services in North Carolina and they have seen a decrease in their Black maternal health mortality, they also saw the gap close in the disparity in

North Carolina. So you should be really proud of your home state for putting that forward.

Ms. ADAMS. Well, I am, you know, of some things. So do you agree that WIC has an opportunity to play a greater role in this conversation?

Dr. CREAR-PERRY. I love our WIC partners. We did a training of implicit bias at the WIC conference last year as well. And so because they touch more moms than most anybody—I mean people go to WIC when they don't go to their pediatrician, when they don't go—they definitely don't go to their postpartum visit to see us, and so WIC is an important partner. They already have boots on the ground and they know the mothers.

Ms. ADAMS. Thank you.

Ms. Sankofa, recently the Department of Labor finalized regulations narrowing its interpretation of joint employment status under the Fair Labor Standards Act, which contains the nursing mother's protections that you discussed. Although the rule does not have the force and effect of law, it tells us how the Department will be enforcing joint employment standards for determining if an employer must comply with these requirements.

What is the impact of this, and especially where the nursing mother has limited ability to take legal action against the employer?

Ms. SANKOFA. I think that is an excellent question and I appreciate it because I really think that it makes it more difficult for the lactating mother to really enforce their right to have a clean and private place to pump and store their milk while they are at work.

As I said at the end of my oral testimony, when employees don't have a clean and adequate safe space, private space in order to pump their milk, they have to make these difficult tradeoffs, and this tradeoff is do you want to stay employed and have economic viability for your family, or do you want to provide the nutritional biological standard for your infant. And I think it is important—we often say that breast is best, while it is true, breast is the nutritional standard, it is what everybody is supposed to have, it is how people are fed, and everything else is actually something that is inferior to breast milk.

Ms. ADAMS. All right. Okay. So protections that entitle nursing workers to break time and private space to express milk are only available to those who are eligible for overtime pay, so who are we leaving out by only protecting who is eligible for overtime pay, and is there a policy reason why these women should not have the right to break time and a private space to express milk?

Ms. SANKOFA. We are leaving out, as I said, up to 9 million workers in the United States. And those are typically salaried employees. That includes people who you know, like if you all have children, you have teachers in your life. So it includes teachers, it includes nurses, it includes software engineers, it includes many of the people who you encounter every day. And I don't know that there is actually a policy reason that these families are not covered by the Break Time for Nursing Mothers law. I think that placement in statute made that gap present. And I think that the PUMP Act gives us the opportunity to kind of right size. We have

10 years of recognized defects within the system to be able to really see where we can take the next step to kind of close that gap.

Ms. ADAMS. Great. Thank you very much, Madam Chair. I yield back.

Thank you for your responses.

Chairwoman WILSON. Thank you, Dr. Adams.

Mr. Walker?

Mr. WALKER. Thank you, Madam Chair.

As I listen today I appreciated the passion of all the witnesses here today. It makes me think of my wife, who is a family nurse practitioner, and her boss, Dr. Lisa David, is the chair there at Wake Forest Baptist Medical Center, and they work with infants and children with cleft palates and do great work. So a quick shout out to them and their work.

Ms. Stewart, you mentioned the increase in the Nation's preterm birth rate to 10 percent. And I am sad to say maybe this picks up with Dr. Adams there, that our home state of North Carolina even has a higher rate, a 10.4 percent, I believe a D rating.

The March of Dimes report card I believe is where that was listed. What would you say attributed to this shift in the preterm birth rate after a decade of decline?

Ms. STEWART. So unfortunately we don't know all the answers of why the preterm birth rate has increased. What we know is that in general health outcomes for moms and babies have generally declined in this country over the past many years. And there are a various number of reasons for it.

First of all, I will just let you know the March of Dimes has six prematurity research centers, five in this country, one in the UK, all working together to try to look at some of the underlying causes, biological reasons why some of this is happening. But we also know that the impact of the way women and families—women especially—live in this country could also have a serious impact. So the degree of stress on women, especially before pregnancy and after, during pregnancy and even after.

We also know that—a lack of access to care. We have too many women living in places where even if they have coverage they may not have care, and those are two different things. So we have, even in a state like North Carolina, places, counties that are considered maternal care deserts where women are not able to access the kind of prenatal care that they need in order to have successful pregnancies.

So there are a variety of reasons for it.

Mr. WALKER. Gotcha. Yeah. You and certainly my wife would know more than I, but I believe preterm or premature birth is defined as before 37 weeks, is that correct?

Ms. STEWART. Before 37.

Mr. WALKER. It is the number one cause of infant death in the United States, with an average of 275 babies being born preterm per week. I know it is in North Carolina.

What challenges or complications can infants face who are born preterm, and what challenges do their mothers face as well?

Ms. STEWART. Well, either I can talk about it or Dr. Joia Crear-Perry can because she has personal experience with it.

Mr. WALKER. Sure.

Ms. STEWART. But we work on this issue as a primary issue for the March of Dimes. As I mentioned, 380,000 babies born every year prematurely, again, before 37 weeks of gestation. What we know is a lot of those preterm births are happening in the period between 34 and 36 weeks, so very late preterm, but some of the most devastating effects happen for a baby like Dr. Crear-Perry's baby, born at a very early preterm stage, so at 21 weeks or 23 weeks of gestation.

And for those babies, the effects can be devastating. Babies can have developmental delays, cognitive delays, physical disabilities, and a whole range of lifelong health complications that are very expensive to address.

One of the things that the March of Dimes did is we updated a study on the cost of preterm birth. About over a decade ago we looked at it at a cost of $26 billion in this country, it is now well over $30 billion. So it has a significant cost of the country from a productivity standpoint, as well as families and those children individually.

Mr. WALKER. Thank you.

Certainly I am someone that believes that life is precious, whatever term that it might be in. I know that is not our discussion today, but any kind of biases before or after something is important to me. And I know, Dr. Crear-Perry, that is kind of your kind of specialty area, if it is; and someone who tries to advocate for all people, I would be concerned about that. So you are telling me that you see biases in there. I want to take that at face value, but I also want to ask you on those biases, do you believe they are intended? Is it out of ignorance? Is it out of an intentional—can you break that—I have got a minute left. I am going to skip my final question because I want to hear from you on that as well, because that is important to me.

Thank you.

Dr. CREAR-PERRY. They are definitely not intended. They are definitely things that we all kind of grew up believing. I believed—I was taught in medical school by my professors that there were three races, mongoloid, caucasoid, and negroid. That was what I was taught. So I believed that the reason that I had a baby preterm is because I was Black, because there was something inately—so that is a bias that we have been teaching that we have to undo, that we have to retrain. As my grandmother would say, we have to unlearn us, right. We have learned some things that are incorrect. So it is an opportunity for us to really—we are all the same. There is no difference between you and I. Our biology is the same. And so how do we then think about what are we doing as a country to ensure that we both have a good outcome?

Mr. WALKER. Thank you, Dr. Crear-Perry. I appreciate your passion in that area.

With that, I yield back to Madam Chair.

Chairwoman WILSON. Thank you so much.

And now Mr. Courtney from Connecticut.

Mr. COURTNEY. Thank you, Madam Chairwoman, and to both Chairs and Ranking Members for holding this hearing.

The topic here today should shock the conscience of every American. And what I want is to just thank all the witnesses. Just that,

you know, you have put forth some really, you know, manageable, doable solutions that, again based on your testimony, I think should encourage us all that we actually have the tools to address this. So, again, thank you all for being here today.

And also that, you know, these two subcommittees I think really, you know, also are positioned to move forward on these issues.

Ms. Stewart, you mentioned—and I think Dr. Perry also in your testimony alluded to the fact that the ACA when it passed obviously moved the ball forward in terms of maternity care, Medicaid coverage, and also the essential health benefits. But I do think, as Ms. Stewart's testimony indicated, I think it would surprise people to know that the age 26 coverage, which is hands down probably one of the most popular, if not the most popular provision of the law, does not extend to dependent adult children in terms of maternity benefits. The number we have is that it is about 4.2 million women, ages 19–25 that are covered under their parents' health insurance plans, again have that gap. And Mercer, which is a pretty credible think tank study, found that approximately 70 percent of employers don't cover maternity care for dependents.

So, again, this is the subcommittee that actually wrote the age 26 provision, because we have ERISA jurisdiction. Again, I wonder, Ms. Stewart, if you could just sort of talk a little bit about how that is maybe contributing to this issue, that gap.

Ms. STEWART. No, I really appreciate it. And I think you are right in that it is certainly one of the most popular provisions in the ACA, that health plans offer dependent coverage for children up to the age of 26. And the inclusion of an essential health benefit—so it is a part of ACA—has also been a huge benefit to pregnant women for maternity coverage. What we know though is the essential health benefits only apply in the individual and small group markets. So these health plans for these large employers who are not required to provide coverage for maternity care for dependents leaves this large gap and this large loophole, about 4 million young women who are covered as dependents but don't have access to this kind of coverage.

So we think that it is very important to deal with this loophole that potentially puts a lot of women at risk, it subjects them potentially to a lot of out of pocket costs if they become pregnant. And certainly this gap in coverage is actually threatening their own health and potentially the health of their baby if they are not able to receive the proper prenatal coverage and the kind of care that they may need. So addressing this loophole will be very important. And it is, again, millions of women that are left in this gap.

Mr. COURTNEY. Dr. Perry, I don't know if you would like to comment as well.

Dr. CREAR-PERRY. As a person who has a 26 year old daughter, I was super depressed when she had to get off my insurance. So I appreciate that exists and that it is popular.

And you think about who gets pregnant, it is 21–26 year olds, and we are leaving off millions by not having this loophole addressed. So it is important for us to recognize if mortality is something we care about and morbidity and parenting and mothering, then we would not leave a space where people don't have access to care.

Mr. COURTNEY. Thank you. I have a 25-year-old, so we are holding on by our fingernails.

And, again, Ms. Wilson, I want to just to again thank you for bringing up the issue of the Ensuring Lasting Smiles Act and the impact of that sort of fragile coverage for congenital birth defects.

I have a letter which I ask to be admitted to the record from Caleb Andrew Lock, who is a 10-year-old just passionate advocate who represents Rhode Island and Connecticut and describes his own situation, which as he points out, if it was caused by a car accident it would be covered, but the fact that it is a congenital defect runs into this obstacle, which is just completely unacceptable.

So, again, thank you for addressing that issue and hopefully that bill will move forward because of the spotlight you are putting on it here today.

And with that, I yield back.

Chairwoman WILSON. So ordered.

Dr. Roe, you know all about this.

Dr. ROE. Thank you, Madam Chair.

And, Ms. Stewart, this has nothing to do with this hearing, but we are working on your pension issue at the March of Dimes, okay?

Ms. STEWART. It only helps us deal with our other issues too. Thank you so much.

Dr. ROE. And I want to congratulate this entire committee. Every one of you finished in exactly 5 minutes, so congratulations.

A few things I want to go over very quickly. And, Ms. Sankofa, I want to get this on the record thanking you for advocating breastfeeding and I think that is a huge thing that you have done. And also to encourage women out there that may be watching this to use the WIC program.

My background, I am an obstetrician. And I have got a little head start on your, Dr. Perry. I have delivered almost 5,000 babies. And one of the things I noticed in my practice, a couple of things that have not been mentioned at all, is obesity and drug addiction.

In our state of Tennessee, in 1998 we had 50 opioid- addicted babies in the entire State of Tennessee. It would have been a rarity to ever see in our—now we have a NICU, of which the surgeon general will be there this Thursday visiting our children's hospital, specifically for opioid addicted babies. And I know absolutely it is depressing to me to see maternal mortality rate in the late '70s being lower than it is today with all the enormous amount of resources and money we have spent.

And would you, Dr. Perry, go—I think it is very important, the definition of maternal mortality and is it described that way, defined that way in other countries?

Dr. CREAR-PERRY. I don't want to mess up the real definition so I could read it again, but how we define it is a global definition. So up to 42 days it is a standard and no matter the site or the—within 42 days of delivery. What we also are starting to do in the United States though is recognize women are dying up to a year later. So although the international standard is 42 days, we really don't have—we know that people die from opioid and substance abuse 3 months later, right. And it is still tied to the pregnancy. So we are now tracking deaths up to a year and really pushing the

international community to start thinking about doing the same thing.

Dr. ROE. Just to give you an example, in our state this year we are trying to take our Medicaid-covered patients, whose coverage in maternal would be out at 6–8 weeks postpartum, and extend that for a year.

Dr. CREAR-PERRY. Yes, yes. Exactly.

Dr. ROE. Because what we are finding is some of these women who are opioid addicted will go overdose later.

Dr. CREAR-PERRY. Yes. Yes.

Dr. ROE. And I think that is important for every state to do that.

Dr. CREAR-PERRY. It is critical. And if you think about us as OB/GYNs, we believed 6 weeks was the magical thing, and so we had insurance end at 6 weeks, but that doesn't match actually the science. The science shows us that women have cardiomyopathy within 6 months to a year later and can die. So all these other things around childbirth are still impacting your body, and there is nothing magical about 42 days.

Dr. ROE. I totally agree with that. And the risk factors that you see for maternal mortality would be age, obviously. Women are older when they have their children. Ethnicity, which you mentioned, obesity, lifestyle, which could be opioids, drug addiction, other things, preeclampsia. We know those things. But why do you see—because to me to have it almost double—

Dr. CREAR-PERRY. Right.

Dr. ROE.—is one of the most distressing things with the amount of money that we put into maternal health in this country.

Dr. CREAR-PERRY. Right. And so it would be a few things. One of them is our lack of investment in community-based organizations and hospitals are—when you practiced, you knew everybody around you, I am sure, and we just don't have that kind of system anymore. So how do we have a system that values the community members who are close and understand the moms, and so really getting back to being close to that.

We also increased our c-section rate, you know that.

Dr. ROE. Yeah.

Dr. CREAR-PERRY. And so a lot of women are dying from hemorrhage and other things after having a c-section. We have one of the highest c-section rates in the world, and we then export that to other countries. India starts following us and having high c-sections too. So we need to really think about why we are doing some of the choices we are doing. And this body has a greater capacity to hold systems accountable for making choices.

Dr. ROE. That was one of the other thing I was going to bring up. I have looked at—when I stopped delivering babies I looked at my primary cesarean section rate.

Dr. CREAR-PERRY. Yeah.

Dr. ROE. And I was trained in Memphis, very similar to where you are in New Orleans.

Dr. CREAR-PERRY. Mm-hmm, yeah, exactly.

Dr. ROE. And it was 8 percent.

Dr. CREAR-PERRY. Yup.

Dr. ROE. Primary cesarean section rate.

Dr. CREAR-PERRY. Yup.

Dr. ROE. Now it is probably 30–35 percent.

Dr. CREAR-PERRY. Exactly, exactly.

Dr. ROE. And the mortality rate is much higher, as we know—

Dr. CREAR-PERRY. Exactly.

Dr. ROE.—in cesarean births as opposed to a natural birth. I would like some firm things. We did this in Memphis many, many years ago. We had neighborhood clinics—

Dr. CREAR-PERRY. Yup.

Dr. ROE.—for women who had a hard time getting—this is urban areas.

Dr. CREAR-PERRY. Exactly.

Dr. ROE. I live in a rural area. And someone mentioned an OB/GYN desert.

Dr. CREAR-PERRY. Yup.

Dr. ROE. I represent four counties and four, almost five, of them have zero obstetrical care in those counties, which means they have to drive long distances.

Dr. CREAR-PERRY. Right.

Dr. ROE. In Memphis we had neighborhood clinics and we had nurses that took care of those. If there was a certain issue, then they were sent to the hospital clinic—

Dr. CREAR-PERRY. Right.

Dr. ROE.—to get evaluated. If their blood pressure was above a certain amount. That seemed to work pretty well when we took the care to—and this was 50 years ago.

Dr. CREAR-PERRY. Exactly. We stopped investing in those kind of things and we stopped in perinatal birth workers. We know community health workers work, we know that investments in people who are closer to the community work, and then you don't have to make people come all the way downtown for a visit. We can now use technology. Telehealth is an opportunity for us to really increase the access. I mean we have so many opportunities. Sometimes we just have to allow for the room for people to build up some of the things that they have learned and that we have been doing on the ground.

Dr. ROE. Dr. Perry, do you think that malpractice—

Dr. CREAR-PERRY. Yup.

Dr. ROE.—has—we haven't mentioned that at all.

Dr. CREAR-PERRY. I know.

Dr. ROE. A lot of young doctors—

Dr. CREAR-PERRY. You and I could talk about this all day.

Dr. ROE. Yeah, exactly. We won't say anything bad about lawyers too much. But anyway, I think that didn't affect me much. I trained in a different time.

Dr. CREAR-PERRY. Yup.

Dr. ROE. But I see our younger physicians—

Dr. CREAR-PERRY. Yes.

Dr. ROE.—that are really impacted I think by that.

Dr. CREAR-PERRY. For sure. People quit practice because—my malpractice insurance was $80,000 a year, and that was—you know, and I had to pay that first before I could pay rent or pay employees. So the cost of how much you pay for malpractice is so prohibitive. And then we are not going to fix maternal health through lawsuits. So that is our current structure in the United

States, if we are going to fix this we just sue our way out of it. And that is just not working. This is an imperative that we really come up with policies that are bigger than lawsuits to fix health.

Dr. ROE. Madam Chair, I want to thank you for having this. We can go on, Dr. Perry and I all day.

Dr. CREAR-PERRY. Exactly.

Dr. ROE. I want to thank you for having this. I think we should continue this, because this is a travesty in the United States to have these kinds of mortality rates. And I do hope we continue this conversation.

Dr. CREAR-PERRY. Thank you.

Chairwoman WILSON. Thank you, thank you. I knew you would be interested, Dr. Roe.

Ms. Fudge from Ohio.

Ms. FUDGE. Thank you very much, Madam Chair. Thank you all so much for being here. It is good to see my friend, Ms. Stewart. Thank you as well.

It is interesting to me that we talk about the number—many of the reasons. Now, let me just say that I am from Cuyahoga County, Ohio and you don't need to go much further than Cuyahoga County and Summit County in my district to see the tragic disparities in infant mortality. There are as many White addicted people as there are Black addicted people, but according to MomsFirst, which is a home visitation program in the City of Cleveland, of the 13,872 births in 2018, 120 infants died within the first year of life. Black babies make up a little over one-third of all of those births, but accounted for more than two-thirds of the infant deaths. And in Summit County, the infant mortality rate among non-Hispanic Black families are more than three times that of non-Hispanic White families. So there is just more than just what we are hearing.

And I am really glad that Dr. Roe likes the whole concept of community health centers, we just need to fund them.

Ms. Sankofa, how can we remove barriers to breastfeeding for Black mothers?

Ms. SANKOFA. The reality is that I think that most of the solutions exist within the communities that are having the problem. And the most important thing that I think that anybody can do is listen to the communities that you intend to serve.

I used to run a breastfeeding project at a different organization and we did implementations of community-level breastfeeding support interventions at 72 community-based organizations and local health departments across the country. And the thing that really made sense was to have a community specific understanding, meaning you have to do some level of community assessment to evaluate what are the systemic and structural barriers that exist for that community. The problem in Cuyahoga County is not going to be the same exact problem in Memphis, and so you have to have different solutions. And I think that those solutions have to be policy systems and environmental change solutions that really look at creating spaces of continuity of care. Breastfeeding happens at the hospital. It needs to be educated prenatally. It happens in the community. And all of those different spheres and spaces where women go, they need to be interacting and speaking to one another in a way that make sure that people don't fall through the gaps.

Ms. FUDGE. Thank you very much.

Dr. Crear-Perry, can you speak to the phenomenon of weathering and its impact on maternal health outcomes for Black women?

Dr. CREAR-PERRY. So although we look fabulous, you know, Black don't crack as we say, on the inside the impact of racism is really bothering our bodies. And Dr. Geronimus for about 20 years has been doing studies that show that we have—work out of UCSF, out of UNC, that shows that the biological impact of racism on our bodies causes us to have higher rates of hypertension, higher rates of preterm birth. And so instead of looking for a pill or a shot to fix weathering, what we can begin to do is hold people accountable, hold systems accountable for things that are harming our bodies, like racism, classism, and gender oppression.

Ms. FUDGE. Pregnant women just don't feel, I feel it here every day.

Let me, before I go any further, thank the organizations in my district that work to help eliminate these disparities. I think it is important for us to say thank you. They are First Year Cleveland, MomsFirst, Birthing Beautiful Communities, and Full Term First Birthday, Greater Akron.

It is important to know that there is help. And so often we don't know where to get help. Because these kinds of agencies and organizations, they just get by, so it is difficult for them sometimes to let people know that they are even there.

You talked, I think, Ms. Stewart, about having coverage but not access. I represent some of the best health care in the world—in the world. Cleveland Clinic, University Hospitals, Rainbow Babies, and I could go on and on and on, yet my people don't have the kind of access they need. You talked about how we get people to a place of health, but it starts way before pregnancy. And so I just appreciate the work that you all do. I thank you and I think the Chairs for having this hearing, because it is an epidemic that nobody is dealing with in any big way. So I hope that I can be helpful in some way going forward, especially because there are so many of my babies that we are losing.

I thank you and I yield back.

Chairwoman WILSON. Thank you, Ms. Fudge. Thank you very much.

Mr. Fulcher.

Mr. FULCHER. Thank you, Madam Chairman.

And I have got a question for Dr. Perry, but I have to share my bias first. I love babies. I like all of them. And I like the name of your group, the Black Mamas Matter Alliance, and I am sure that probably extends to the Black Babies Matter Alliance too, so it is great.

We know that women of color have about a three times more likelihood of having an abortion than not. And that is kind of—I wanted to just talk to you about that because we are confronted with a situation where in this case Planned Parenthood is the number one provider in that, and just historically they have targeted that community, the women of color community, and they provide many more abortions there than elsewhere. And that is just wrong to me. And it is just—the data is so obvious. And why women of color? And why do they target there? And it just seems

unconscionable to me that people are making money off that and somehow we tolerate it. And I just wanted to get your thoughts.

Dr. CREAR-PERRY. I am not a representative of Planned Parenthood, although I work with them extensively. So I am speaking on behalf of Joia and not the organization.

So how black women interact with health care is a lot based upon the history, historical injustices and oppressions. And so perhaps instead of thinking it as they are being preyed upon by Planned Parenthood, that we are being provided a service because we don't have access to Medicaid expansion in some states, we don't have access to all the other services, we don't have hourly wage jobs that we can leave, so we don't have all the social things that people need to be able to make different choices around birth options.

Mr. FULCHER. The result of that is that we are losing babies.

Dr. CREAR-PERRY. Exactly. So the result of us not making choices in this building to support Black women means that Black women have to make a lot of different choices around their bodies.

So if we decided that we believe that we should have access to paid leave, maybe that would impact who chooses to have an abortion or not. Like there are choices that you all make here as policy makers that impact how we can live our lives. That is much more impactful upon our lives than any one organization like Planned Parenthood. They are one small organization, you are the government. So how you decide to support women and how you decide to support Black women and listen to Black women, really matters way more than what Planned Parenthood does.

Mr. FULCHER. Thank you.

Madam Chair, if I might just follow up.

And I hear what you are saying and that makes sense. At the same time, I don't think that crosses their mind one little bit. I don't think they care. I think that their whole deal is looking at the bottom line, because that is—when we get approached for funding and we get that kind of pressure, all right, I understand the point you are making, but I am just trying to communicate a point. I don't think they care one bit.

Dr. CREAR-PERRY. So I am going to give you a counterpoint. Our wonderful congresswoman from Cleveland mentioned Cleveland Clinic. They choose not to open labor and delivery in the part of the city where they had—their big hospital is because they don't make money there. They have a labor and delivery in the suburbs, right, so they have their hospital that is in the neighborhood that needs the most care for pregnant moms. They make a choice to say we are not going to do any labor and delivery here, we are not going to provide services for the people in this community.

So I would say that most organizations, big health care systems, make choices based upon money and that is a choice that the United States has made in general around how we provide care. If we took that conversation outside of where you can make money—because I could go back and forth with you about all the systems and where they choose to put clinics, where they choose to put hospitals. Those are choices based upon money, based upon choices around Medicare and private insurance that are made here; that we could make very different choices.

Mr. FULCHER. Thank you, Madam Chair.

And I will close my comments. And thank you, Dr. Perry. I will just say this. Let us agree on this.

Dr. CREAR-PERRY. Okay.

Mr. FULCHER. Maybe that is a two-pronged approach, because I think you bring up some good points and to the extent I and colleagues can be supportive of that, then I am happy to try to do that.

And at the same time, for those who I am convinced are preying on our community of color, I am not supporting that. And so please know you are appreciated, your work is appreciated.

Dr. CREAR-PERRY. Thank you.

Mr. FULCHER. And hopefully we can work together on a two-pronged approach to try and make things better, okay?

Dr. CREAR-PERRY. Sound great. Thank you.

Mr. FULCHER. I yield back. Thank you.

Chairwoman WILSON. Mm-hmm. Thank you.

Mr. Takano of California.

Mr. TAKANO. Thank you, Madam Chair, Chairwoman Wilson and Chairwoman Adams for this critical hearing on maternal health and infant health.

The United States has some of the best physicians, hospitals, and groundbreaking medicine in the world, and yet it is also the most dangerous and worst place to give birth among any of the developed countries. A 2019 report from the Centers for Disease Control and Prevention found that three in five pregnancy related deaths could have been prevented. And unfortunately, the number of infant and maternal deaths are increasing every year. We know there is a link between having access to health coverage and the decrease in maternal mortality and severe maternal morbidity. A report by Georgetown University's Health Policy Institute found that in Medicaid expansion states like California, they have seen decreasing maternal and infant mortality rates.

Madam Chair, at this moment I would like to ask unanimous consent to enter into the record the report from Georgetown University.

Chairwoman WILSON. Without objection.

Mr. TAKANO. Thank you, Madam Chair.

My first question is for Ms. Stewart. Ms. Stewart, what benefits do you believe extending Medicaid coverage for mothers beyond 60 days will have?

Ms. STEWART. Well, thank you for that. And I appreciate you raising that issue of the CDC study that said that three out of five of the cases of maternal death could have been avoided, and it could have been avoided with improved care, not having delayed or misdiagnoses, and a whole range of other issues. So we know that this issue is completely within our ability to control.

We also know that the issue of maternal deaths is spread across the period of time from pregnancy, right at the time of the childbirth, and then from the period of time from one week out from having the baby out to 1 year.

When we look at the issue of Medicaid coverage, we know that for many women who actually were able to receive Medicaid coverage for the birth of their child, after several months over 50 per-

cent of them are often dropped from Medicaid coverage, which means that they have had chronic health challenges, even some that were exacerbated, or any health challenges exacerbated because of pregnancy or childbirth, they are often left without coverage.

And so the idea of expanding Medicaid coverage for all women, and for not only during the period of the childbirth, but for women to make sure that they have the care that they need, both in terms of their physical conditions, but also their mental health conditions as well, because a lot of the challenges that women may face often are not just as a result of issues that affect their health, maybe related to obesity or hypertension, but also due to mental health concerns as well.

So we think that the ability and the need to have to extend Medicaid coverage to make sure that women have the coverage they need out to 1 year is essential in terms of dealing with the kinds of postpartum challenges that many women experience after having birth.

Mr. TAKANO. So, again, the reasonable length of time that coverage should be extended is?

Ms. STEWART. We propose, and I think there is a lot of agreement that out to a year is really important.

Mr. TAKANO. To a year? To a year?

Ms. STEWART. A year.

Mr. TAKANO. What can we learn from other developed countries that have lower mortality rates? What do we know?

Ms. STEWART. So I think—and I mentioned it earlier—I mean think there are a lot of things that we can look at. One is that, you know, a lot of countries actually have far more supportive policies for families. So issues like paid family leave, more supportive policies within the workplace, really more extended care for women, access to other alternative forms of care, like midwives have been really important and really productive effective ways to help women have more successful pregnancies.

Mr. TAKANO. Thank you.

As Chairwoman Adams has stated, nursing workers that are eligible for overtime pay under the Fair Labor Standards Act are entitled to break time and a private space to express mother's milk. This is an important workplace right that helps promote the health of both the baby and the mother.

Ms. Sankofa, when an employer violates a nursing mother's right to break time and private space to express milk, how can the nursing mother hold her employer accountable?

Ms. SANKOFA. Thank you. That is actually a really difficult thing for the actual employee to do. There is a significant gap that has surfaced in terms of remedial measures related to the break time law. The employee has to reach out to the Department of Labor, Wage and Hours for the Department of Labor to express that they are—to file a claim and then the Department of Labor has to investigate whether or not there was an actual violation. And before anything extra can happen, the Department of Labor actually has to take the step to take it to court or not.

And so when it goes to court there is nothing that mothers actually get from that process typically because it is for—the break

time law is not necessarily a paid aspect of that process. And so there is no actual thing that you get back even if it goes to court via the Department of Labor.

And so I think that—

Mr. TAKANO. Thank you.

Mr. TAKANO. So I think that movement to the PUMP Act is a very efficient way of trying to create a space where the traditional spaces of the FLSA can be implemented so that the same type of remedial actions that exist for other violations of employee accommodations—employers already know how to work with this and this puts it within that same level of statue within the law.

Mr. TAKANO. Thank you, Ms. Sankofa.

I am sorry I went over. Madam Chair, I am yielding back. I just want to acknowledge the work of Barbara Anderson, a constituent of mine who has done tremendous work on this topic as a nurse midwife who has been a scholar and researcher.

So I apologize for going over. I yield back.

Thank you. And thank you for the answer, Ms. Sankofa. Very helpful

Chairwoman WILSON. Thank you. Thank you very much.

Dr. Foxx.

Ms. FOXX. Thank you, Madam Chairman.

I have great respect for my colleague from Tennessee and I yield him 30 seconds.

Dr. ROE. Just very quickly, we don't have enough people breastfeeding, we have a maternal mortality rate that is too high. Why don't we take a public health approach? Remember only you could prevent forest fires? We all remember that. If you are old enough you do. Why don't we have a public health approach to educate the public and the country? I will bet you that most Americans have no idea that the mortality rate is that high. So why don't we look at the surgeon general, March of Dimes, and so forth and do a public health education approach to our people in the country?

I yield back.

Ms. FOXX. Thank you, Dr. Roe.

Ms. Stewart, as we like to say in this committee, states are the laboratories of innovation, most often for the better, but sometimes not so. We can learn a lot from what states are doing to address infant and maternal mortality and find out what works and what does not.

What state initiatives are underway to address infant and maternal mortality? What are the preliminary results of these initiatives and programs?

Ms. STEWART. Well, I actually think one of the states that has probably had the most success on the issue of maternal mortality for sure has been one that was mentioned earlier, in California. California was one of the early states to actually create what essentially is now one of our maternal mortality review committees and actually use data to actually drive decisions on where maternal deaths were happening and what interventions—working with health care providers, working with hospitals, and others to make real progress. They have made measurable progress over many years. They still are working on some of the inequity issues that they experience. In other words, they saw large decreases in terms

of maternal deaths, but they were still seeing unacceptable—and they are still seeing unacceptably high rates—not to speak for them—unacceptably high rates among those women of color.

So I think there still are—I think one of the most important things that we have not done as a country and in states is have the appropriate data, which is why I go back to the action that you all took to create maternal mortality review committees. It has been a huge step forward. But now that we are learning more, we can do more to actually prevent some of the causes and the underlying causes of death.

Ms. FOXX. Well, thank you. And I think there has been a huge emphasis in this Congress in the last 3 or 4 years on evidence-based decision making. We have talked about it in all areas. We want to be able to do what works instead of just throwing money at programs for the sake of throwing money at programs or thinking our district deserves a certain amount of money. We really do need to be using our scarce resources very, very wisely.

Let me ask you another question, Ms. Stewart. As we consider this important issue from the perspective of this committee and examine potential solutions which are in the jurisdiction of this committee, how can employers and health plans work with providers to support decreased maternal and infant mortality? We have heard from employers about partnerships with other organizations, including the March of Dimes, to promote value-based care, reduce unnecessary interventions, increase transparency around provider quality. Are you aware of any partnerships among providers, employer- sponsored health plans, and organizations that are working to improve the quality of maternal health?

Ms. STEWART. Well, I think there are a lot of employers that are becoming much more aware of some of these issues. And I think one of the things that I mean you all have the ability to impact, and one of the policies that I think is most effective in terms of providing the support that often families need, is around paid family leave. It is not the only thing, but it certainly is one thing that can make a big difference. If a woman has had a problematic pregnancy, if she is having to stay at home to take care of a child, she should not have to be forced between having to return back to work or stay at home to take care of her baby and then face income interruption that could be devastating to her family.

So I think the kinds of accommodations that would be provided by making sure that there is sufficient paid family leave for a woman to have to deal with maybe her own health issues or the health issues of a baby are incredibly important.

I also think that a lot of employers are now much more aware of some of these issues than ever before and are open to making sure that there is more information and more awareness, as was mentioned earlier, around some of these challenges. And I think the more and more that we can pursue building the awareness and expanding public education—we have had at the March of Dimes an incredible relationship with the CDC to provide broad information to the public around a lot of health challenges as it relates to maternal and infant death. We think we need to do more of that.

And then the last thing I would just say is I think a lot of employers have a vested interest in this. When a baby is born pre-

maturely it has a significant cost to that employer. And so a lot of employers are very—and even when a mother has her own health challenges, if that employer is left without a productive worker or if that mother dies and is no longer there, there are significant costs to the employer. So I think there are tremendous opportunities to go to employers and look for partnerships to expand the kind of information and access to care that women need and the families need.

Chairwoman WILSON. Thank you very much.

Ms. FOXX. As I have said before, I think that employers understand what you are talking about and that any time an employee is out there is a significant loss to everyone. And so I do think there is a great deal of concern on the part of employers for their employees and they would like to do things that make it better for everyone concerned.

Thank you, Madam Chairman. I yield back.

Chairwoman WILSON. Thank you.

Ms. Jayapal.

Ms. JAYAPAL. Thank you, Madam Chair.

Thank you all so much for your excellent testimony. Very, very powerful. And I can tell you, as a mom myself who delivered my kid at 26 1/2 weeks, 1.14 ounces, serious threat to my own mortality and certainly to theirs, and morbidity, this is an issue that I have worked on myself and followed for a long time.

I think we are, you know, the richest country in the history of the world and we spend by far the greatest amount of money on health care, and yet we have such abysmal health outcomes, as you have gone through.

And I completely agree with you, Dr. Crear-Perry, when you said that we should expect more, that we should demand more, and that we must address the maternal mortality crisis in this country, and that we have to do so by clearly calling out the racism and discrimination within our existing health care system that makes it so much more dire for communities of color and especially for Black mothers. So thank you for that.

Let me start with you, Dr. Crear-Perry. Your testimony illustrates how for-profit insurance and payment systems have a significant impact on maternal health outcomes. Can you talk to us about how high out of pocket costs, like private insurance premiums, copays, and deductibles, exacerbate racial inequalities in our health care system?

Dr. CREAR-PERRY. Well, you know, the data shows us that Black women, despite income or education, are more likely to die in childbirth. So that means that most of the Black women who are receiving care are not on Medicaid, they are the private insurance payers that you all have legislative power and authority over. So when you allow for those institutions to charge huge deductibles, when you allow for those institutions to say that we are not going to cover your child when your child is pregnant, you are allowing those organizations to then harm women, specifically Black women, because we are also so exposed to having morbidity and mortality in childbirth.

So it is important for us to not only think about governmental insurance when we talk about this maternal mortality crisis, be-

cause we, all three of us sitting up here, just as well as you, have education and access and we still have poor outcomes, right. So it is important for us to really think about our private insurers and the choices that they make that harm our bodies.

Ms. JAYAPAL. And can you also talk to us about the huge gaps in coverage for prenatal services, doulas, patient support for after birth, and home care if we had a plan—as my Medicaid for All plan does—

Dr. CREAR-PERRY. Exactly.

Ms. JAYAPAL.—provide comprehensive services of this nature? How would that benefit maternal health outcomes?

Dr. CREAR-PERRY. Because we talk a lot right now about improving doula care. And I usually hear that conversation in the Medicaid population. And once again, it leaves off that we don't cover any of these things for folks on insurance. I, as a city employee who ran a city health department, had to negotiate with the insurance company around coverage for my staff. People don't realize there is an individual who is making choices for your care at your job. They are negotiating with the insurance company and they are deciding what they are covering. We could make a rule that they have to cover doulas and they have to cover midwifery and they have to cover them at parity. Those are choices that one individual at your job should not be making for you.

Ms. JAYAPAL. And if every person had guaranteed coverage of comprehensive services under a universal health care system, like Medicare for All, with no cost barriers, what do you think would happen to the impact on reducing or even eliminating disparities in health care access and outcomes?

Dr. CREAR-PERRY. We see a little bit of a glimpse of what that would look like in places that did expand Medicaid. We see an improvement in outcomes just with that one small ask. Even in a program that is chronically underfunded, that people don't have a lot of access with, we still see improvements in outcomes. So if everybody had access to insurance and coverage, then we would see an even bigger uptick of what we could look like as a country to the rest of the world to show that we are really all that we dream to be.

Ms. JAYAPAL. I really thank you for your testimony. I think, as people know, I have been pushing for a universal health care system because I believe it is not out of reach, it is what other countries do. We certainly spend enough money that we should be able to do it here. And that would mean that we are all guaranteed the same level of high-quality comprehensive coverage with no premiums, co-pays, and deductibles or out-of-network doctors.

And also, by the way, a more efficient system for our safety net and rural hospitals as well.

Madam Chair, I seek unanimous consent to enter into the record a letter from a coalition of racial justice organizations, including the NAACP, LULAC, and the Black Women's Health Imperative, making the case for why Medicare for All is a racial justice issue.

Chairwoman WILSON. So ordered.

Ms. JAYAPAL. Thank you, Madam Chair.

And I just want to thank you all again for your excellent testimony and for lifting up the issues that particularly Black women

and women of color face and this critically important issue that we all need to push for immediate action on.

Thank you. I yield back.

Chairwoman WILSON. Thank you. Thank you.

Mr. Johnson.

Mr. JOHNSON. Thank you, Madam Chair. I would start by noting that yesterday, as I was eating my Wheaties, I read an excellent article by the South Dakota News Watch that printed in my local newspaper, the Mitchell Daily Republic, and it dealt with this very issue. And I thought it was an in depth and insightful piece, and so I would ask unanimous consent to introduce into the record, "Effort Begins to Reduce Risk of Death of South Dakota Mothers During Childbirth" into the record.

Chairwoman WILSON. Without objection.

Mr. JOHNSON. Thank you very much.

This is probably for your, Doctor, but if any of the panelists want to weigh in, I would be interested to get their take as well. I was intrigued by some of the best practices that this article brought out, things that seemed to me to be relatively low hanging fruit. I will give a couple of examples. Weighing blood absorbing pads so that we can better ascertain how much blood loss a mother has had during childbirth. That doesn't seem very difficult to implement.

Dr. CREAR-PERRY. Exactly.

Mr. JOHNSON. Blood pressure cuffs, so that medical professionals can have real time information. So if they forget, if the Ms. a measurement time, they are still alerted to when that mother—when we have got a blood pressure problem.

Again, I view this as relatively low hanging fruit. When you look at the implementation of these practices across the country, on a scale from 1, being we are not doing any of them, and 10, we have perfect implementation of these best practices, where do you think we are as a country?

Dr. CREAR-PERRY. Yeah. Oh, man, 3 1/2 maybe. The good news is because—

Ms. STEWART. Two.

Dr. CREAR-PERRY. Two? Yeah. I mean you bring up the blood loss one. So as an OB/GYN we weren't measuring blood loss that way. You might be surprised to know that we would do things like look and say, ah, looks about like 1,000 milliliters. Like that is how we estimated blood loss. So it is a big shift in practice to actually weigh and measure the pads. So what you then have to do is say to the people who feel like, well I have always done really great care, that you—actually women are dying because we are not doing this correctly as a field. This is a systems change, this is not about you as an individual and the care you provide, but a systems change. So that system shift has been difficult because people still believe in their own individual, that they as an individual provider are doing great things. So having legislation, having standards by governing bodies then makes for room for implementation to occur. As long as it is optional—and I will even go back to the—it was exciting to have the CDC give money to states around maternal mortality, but we don't require it, so that is why you still have three states who haven't done it.

So there are times that we need government to act, to put together policies that require things, like you need to count the blood loss.

Mr. JOHNSON. Yes.

Ms. STEWART. Can I add to that too? Because I think those are practices, like measuring, monitoring whether or not women are hemorrhaging and how much they are hemorrhaging, so that we actually know how at risk they are. After they have had the baby they go home and they are experiencing problems that were not dealt with when they were in the hospital.

But the real issue is that we have to—we are not going to deal with the issue at the point of a woman almost at the point of death, right. I mean if she is hemorrhaging to the extent, she is so close to potentially losing her life. The issue is how do we move more upstream, how do we address these issues of women's health before they are pregnant? What we find is that increasingly more women that are pregnant have chronic health conditions, they are obese, hypertension. One of the leading causes of death for women as a result of pregnancy and childbirth are heart-related challenges. So how do we make sure that women are able to manage their health before they are pregnant so that they don't have these problems exacerbated as a result of pregnancy and childbirth?

Mr. JOHNSON. So maybe a follow up, Dr. Crear-Perry. You know, we mentioned standards and national bodies. You know, this article talks about the joint commission, which I think has some oversight or engagement with they said about 80 percent of hospitals in the country. I mean if I am looking to some repository of best practices, if I am looking to a source that really has it right, is the joint commission a good place for me to pay attention to?

Dr. CREAR-PERRY. So I was on the Joint Commission task force to create those measures. And so I think there are people in that room—the American College of OB/GYN has the AIM bundles. It is a great place where you can look to find a repository of best practices. And that is really who through HRSA has been funded to build the policies out. The CDC has the Perinatal Quality Collaboratives, and they really need more funding to uplift those collaboratives. In South Carolina they are doing—I just spoke at your annual meeting around maternal mortality in South Carolina—and really having more investment in the Perinatal Quality Collaboratives would be so important. Because you get the numbers and the data and someone has to implement it. So who is going to say to the people in South Carolina, are you measuring your blood loss? It is going to come from that Perinatal Quality Collaborative who needs support from legislation.

Mr. JOHNSON. Well, thank you very much.

And, Madam Chair, what an important topic and what a meaningful conversation we have had.

Thank you.

Chairwoman WILSON. Mr. Morelle from New York.

Mr. MORELLE. Thank you. I find it completely unacceptable that 1 in 700 American women dying of pregnancy-related causes each year and tens of thousands facing severe health implications. So I appreciate very much, Madam Chair, you and the Ranking Mem-

bers for convening this hearing today to talk about what we need to do to protect mothers and children.

There has been a lot of conversation about what goes on in other states, so I just want to just share a little bit about what we are doing in New York if I can get a little equal time for the Empire State.

We have actually made I think significant improvements. We were just a decade ago I think about 46th in the Nation, which is really obviously just a horrendous number, but we have now moved up to 23rd, at least as it relates to maternal health outcomes. We have made significant investments in the last decade. Today we have 86 hospitals participating in the New York State Perinatal Quality Collaborative, which better assesses and manages obstetric hemorrhage. Last year we took steps to create our own maternal mortality review board, building on the success of collaborations in many other states that have been mentioned here today. But we still have a long way to go.

And I note that my son and daughter-in-law are expecting a grandchild very soon, so I am really paying attention to a lot of what you are talking about today, more than perhaps I knew about when I was an expectant father. But I do, after the testimony, and I do want to get to a couple of different questions if I might.

First, Ms. Stewart, obviously it has been talked about, the estimated 60 percent of all maternal deaths could have been prevented. I am interested, I understand in the state of California and elsewhere hospitals have found success using simple innovations, hemorrhage carts, quantitative blood loss, elective c-section reductions, all methods that resulted in lower rates of death as I understand it among pregnant women in hospitals. And I am just trying to understand what are some of the changes that can be made among the medical community that relates to providing care during pregnancy and delivery first and foremost. I know that there is the post, but I am just curious, during delivery and immediately after—during pregnancy, delivery, and then immediately after. If you could talk about some of those impediments or barriers.

Ms. STEWART. So I think one of the things that we have to realize is that women have been having babies for a long time before hospitals existed.

Mr. MORELLE. Now that may be the truest statement ever said in a congressional hearing.

Ms. STEWART. This has actually been going on for a while, and even before hospitals were even around. And what existed—now, there were some not great outcomes before and hopefully our medical community has really sought to look at ways it can improve those outcomes over time, but one of the things that we found are some unintended consequences. One of the things that Dr. Crear-Perry mentioned is dramatic increase in c-sections, right. So 1 out of 3 deliveries now is by c-section. And we know that puts that mom's health at risk, right.

Mr. MORELLE. I am sorry to interrupt, but in recent years has that number gone up or down?

Ms. STEWART. It has been going up.

Mr. MORELLE. Still, continuous?

Ms. STEWART. It has been going up. We actually at the March of Dimes had a big influence on the number of elective c-sections, which we actually were able to see a decline in elective c-sections. Especially during the period of time before this last 4 year period of an increase in preterm birth rates we were actually seeing a decline. And we think a big contributor to that may have been a reduction in elective c-sections.

Mr. MORELLE. I see.

Ms. STEWART. But we are seeing overall c-sections increase and it is not often, you know, fully elected by the mom, right.

One of the things I think that we can really look at is the fact that we can go back to some practices that actually did work for us in the past before we had a very medicalized process of delivering babies, right. So in New York, you all are doing a whole experiment on doulas as a part of the Medicaid program. We think and we encourage health care professionals, medical professionals, doctors, to have better relationships with midwives and with doulas. Studies have shown that doula care can often reduce the level of c-sections, can increase and improve health outcomes for moms and babies. We think that if these kinds of services were more available, maybe in addition to their traditional medical care, we could probably see some outcomes improve over time.

Those are just some of the things that—

Mr. MORELLE. Right. Thank you.

And I only have a few seconds left, but I did want to hear Dr. Crear-Perry, the issues of unconscious bias related to both gender and race affecting pregnancy-related care, could you just talk a little bit more about that?

Dr. CREAR-PERRY. Yeah. I mean I have the pleasure of working with your staff there in New York around this work. And they are doing some trainings with their staff because what we are recognizing is unconscious bias makes us do things like if we believe it is a Black woman and their blood pressure is 160/90, the hospital will say, oh, but they all kind of run high, so they won't treat it. And then the next thing you know, that woman is seizing and in the ICU. So the bias around believing that we all kind of have hypertension when we don't is killing people.

So those are kind of the important things for us to be able to unpack.

Mr. MORELLE. Great. Thank you.

Thank you, Madam Chair. I do ask unanimous consent to submit into the record a letter from Johnson & Johnson applauding this subcommittee's leadership in addressing the urgent health crisis that affects families around the country and expressing their commitment to the goal of eliminating preventable maternal deaths globally.

Chairwoman WILSON. Without objection.

Ms. Wild from Pennsylvania.

Ms. WILD. Thank you, Madam Chairwoman.

First, I just want to thank this panel for not only the content of your written testimony, but the passion that you bring to this subject, very easy to listen and absorb what you have said. And it is just such an important subject. I feel as though in a country where we say that we value family values so much, that we often miss

the boat when it comes to policies and accommodations and efforts that need to be made to truly promote family values, and of course maternal health is key to that.

And I appreciate the systemic approach that all of you seem to have adopted to the problem of America's maternal and infant health crisis, because it seems to me, both in my own thinking but also you have fleshed it out for me in your testimony, that it really has to be a holistic approach, it has to start very early in life, it has to start with education, it has to start with making sure that young women and men are able to get a good education so that they can go on to get good jobs where they have more flexibility and hopefully better health care benefits and that kind of thing. We have to make sure that our workplaces are safer and that workplace accommodations for pregnant women and new moms are made. We need improved health care from all perspectives, not just pre and postnatal care, but overall preventive health, whether it be blood pressure checks, routine mammograms, immunizations, gynecologic care, and that kind of thing.

So with all of that said—none of that was a question—but I want to ask—and I could ask any of you these questions because you are all very well qualified—but let me just start with Dr. Perry.

I won't ask it ask it as a leading question. Do you believe that better access to contraception is an important component of women's health?

Dr. CREAR-PERRY. For sure. We know for sure that if you don't have access to be able to make choices around your body that you can enter care later, you can enter care sicker, that you are not making fully informed choices for yourself. And so I love that you used family value. So the value of valuing what the woman wants and valuing what her needs are and meeting her wherever that is. And you can have your own beliefs in your own house, but our job really is to support what people believe for themselves and what they want for themselves.

Ms. WILD. And before we even get to the issue of contraception, I assume you feel the same way about sex education—

Dr. CREAR-PERRY. Yes.

Ms. WILD.—both in the schools and outside the schools—

Dr. CREAR-PERRY. Exactly, exactly.

Ms. WILD.—throughout our communities?

Dr. CREAR-PERRY. Yeah. And it is important as a person who—you know, as a mother and as an OB/GYN, so many patients don't know basic information about their bodies and we are expecting them to navigate a world where we haven't given them the tools to be able to do that.

Ms. WILD. Right. And same thing with the protection against intimate partner violence.

Dr. CREAR-PERRY. Yes, for sure.

Ms. WILD. And, Ms. Stewart, I will address my comments to you, just because I see you nodding. That is a similarly important component of this, am I right?

Ms. STEWART. It is important. And I just want to mention one thing on contraception too. Science tells us that one of the most effective ways to reduce preterm birth if a woman has had a preterm birth already is to ensure that there is appropriate birth spacing.

And that means that a woman has to be given the ability to make the choice as to when she has a baby. And certainly ensuring that there is an 18 month gap at least between the time when she has had a baby and the time that she becomes pregnant again has been proven to actually reduce the risk of a subsequent preterm birth.

But we also know that protections around intimate partner violence are really important. I mean we have seen an increase—I live in Maryland and we saw a dramatic increase in the kind of violent activity targeted towards pregnant women and our state took action there. And I think it is important that at a Federal level we address the fact that too many pregnant women are subject to the kind of violent treatment by their partners or significant others that really put them at risk and then also put their babies at risk too.

Ms. WILD. So Dr. Perry—I am switching back—am I correct that not all health plans, even under the ACA, cover the services that we have just talked about?

Dr. CREAR-PERRY. For sure. And, you know, it is just really frightening to think that we have made so many steps forward, but we keep getting steps back. So really making a commitment for people to have access to all the services would be important.

Ms. WILD. So my colleague, Mr. Fulcher, across the aisle commented on Planned Parenthood.

Dr. CREAR-PERRY. Yes.

Ms. WILD. And my question to you is what is the role of community health centers and places like Planned Parenthood to fill these gaps in services?

Dr. CREAR-PERRY. Right. So because we do not have a universal health care system we need players like Planned Parenthood and others, we need organizations like Federally Qualified Health Centers. Here in DC there is an FQHC that has a birthing center inside of a Federally Qualified Health Center with a Black midwife, Ebony Marcelle, who is running this center, to have a full range of reproductive options. Also in Memphis there is an option.

So we need the Planned Parenthoods, we need the clinics, we need quality care provided for people in their neighborhoods who—and all their needs met across the reproductive spectrum.

Ms. WILD. Thank you very much.

My time is up. I yield back.

Chairwoman WILSON. Thank you.

Ms. McBath from Georgia.

Ms. MCBATH. Thank you, Chairwoman Adams and Chairwoman Wilson. I appreciate you both for being so instrumental in highlighting the need for transformative maternal health in this country. And I also want to thank the panel for coming to address Congress on this very, very pressing issue.

And we all know the statistics, so we don't have to go over them again. We have all seen the failure to make progress on this problem. That is the reason why you are here today. This problem runs far deeper than many want to even acknowledge and we have a responsibility to these families to make sure that their safety and the health is the number one priority.

Research is clear, access to care and other socioeconomic factors play a significant role in maternal mortality rates in Georgia and

throughout this country. And actually Georgia has the second highest maternal mortality rate in the country.

Dr. Crear-Perry, what should we be doing to ensure that women have access to not only the health care, but also the other supports that they need to be healthy during pregnancy, childbirth, and postpartum?

Dr. CREAR-PERRY. Well, it is exciting to see—thank you—that there is a move to extend Medicaid for a year. I think Georgia is one of the states that could really benefit from that. Having not done Medicaid expansion, really letting the science show us that you need to have insurance for at least a year after you have a baby, so that would be an important move.

I think also in Georgia and other states, looking at our policies around access to work leave, it is not even just when you have the baby. If you are a high-risk pregnant person, you need to go to the doctor more often. If you are choosing between your hourly job and being able to make twice a week appointments at a doctor's office where you sit for four and five hours at the waiting room, right. You don't have time for that, you have to go to work. And so when do we make room for paid leave and structures that allow for people to be healthy, not just when the baby comes home, but caring about mom while she is pregnant?

Ms. MCBATH. Thank you for that, because I was a high-risk pregnancy myself and actually had to take short-term disability—

Dr. CREAR-PERRY. Exactly.

Ms. MCBATH.—because when I was working as a flight attendant there were no particular considerations that were made for us as pregnant women.

Dr. CREAR-PERRY. Exactly, exactly.

Ms. MCBATH. So I had to go on short-term disability just to be able to make sure that I brought my son into the world.

Dr. CREAR-PERRY. Exactly.

Ms. MCBATH. A few months ago I worked with Representative Gwen Moore, Tom Cole, and John Katko to introduce the Family Violence Prevention and Services Improvement Act. As you know, FVPSA provides necessary funding to help survivors of domestic violence, and it should not go unaddressed today that there truly is a correlation between intimate partner violence and maternal health.

Dr. CREAR-PERRY. Yup.

Ms. MCBATH. Dr. Crear-Perry, can you share more about why pregnancy puts women at a higher risk of experiencing intimate partner violence?

Dr. CREAR-PERRY. Yeah. So we know that the stressors that are impacting mom are also impacting dad. So we want to move to a space of restorative justice, right. How do we think about intimate partner violence in a lens of if we don't provide supports for families for people of color across the United States, when a mom gets pregnant, you are going to see dad act out, you are going to see the partner act out and become more violent because they don't have the resources they need and they feel very—that they can't meet the needs of what they are supposed to have done. If we really want to improve intimate partner violence, if we really understand why it happens, that people are not just mad and sad and acting

out, but they are a part of a larger system, then important for us to invest in both moms and making sure they are safe, and really thinking through how are we educating our sons. I have two. What are we doing around people and their access to how they think about pregnancy and birthing in their communities.

Ms. MCBATH. So let me go on and ask you what are some of the health consequences of intimate partner violence for pregnant women and their infants?

Dr. CREAR-PERRY. Yes. We know in some states it is one of the top leading causes of maternal mortality, right. In our own state of Louisiana, my home state. So we could look and see a policy choice. If you say if I call the police, if I live in HUD housing or in Section 8 housing, because of intimate partner violence I can get kicked out, when I am pregnant that rule makes me at higher risk of actually dying, right. Because I am afraid to lose my place I am not going to call anybody to come. And so that is a policy change that improves it. So we lobbied or we advocated for getting rid of that rule, that people cannot be kicked out of Section 8 housing because they are calling the police for domestic violence. That improved the outcomes for Black women who were pregnant in the State of Louisiana.

So those are the kind of policy choices that are not around individual choices, but you are putting people at risk of harm when you create solutions that don't think through what will happen to someone who is impacted.

So morbidity and mortality, having risk of death is the highest risk that you can have, and it is really high during pregnancy.

Ms. MCBATH. Thank you so much.

I yield back the balance of my time.

Chairwoman WILSON. Thank you.

Ms. Underwood of Illinois.

Ms. UNDERWOOD. Thank you, Madam Chair.

On January 28, 2017, 3 years ago from today, I lost a friend. Dr. Shalon Irving was a classmate of mine at the MPH program at Johns Hopkins University. She went on to become a CDC epidemiologist, a lieutenant commander at the U.S. Public Health Service Commissioned Corps. She was highly educated, financially secure, surrounded by a strong network of family and friends. She was covered by quality health insurance. She is a Black woman and she lost her life 3 weeks after giving birth to her baby girl, Soleil, her first child.

Three years after that tragedy we are here to address a crisis that cuts across education levels, income brackets, geographic regions, and type of insurance. Moms and babies are losing their lives at unacceptably high rates in the United States. And families like Shalon's are left picking up the pieces.

The name of today's hearing is Expecting More. And when it comes to America's maternal and infant health crisis, we need to expect more. We need to pay more attention, take more action, and make more progress.

Ms. Stewart, through your work leading the March of Dimes you have heard too many stories like Shalon's in America. Why are protective factors, like education and wealth, failing to insulate Amer-

ican moms from elevated risk of maternal mortality and severe morbidity?

Ms. STEWART. So, first of all, I am very grateful that you tell that story and that you celebrate the life of your friend who unexpectedly and wrongfully has passed away and unfortunately is no longer with us. And I think the point you are raising around the maternal mortality rate for Black women as it relates to no other issue other than the racism that they probably experience as a result of their health care experience, is really one of the most critical issues that we have to talk about in this country.

The fact that we can look at an educated Black woman and she dies at a rate that is five times more than her White counterpart, is just simply unacceptable. And if it is not due to their income level, it is not due to education level, it is not due to medical coverage or health care coverage or insurance, or all these things, then what else is it? It has simply to do with how they are being received and treated by the system where they are expecting to receive quality care and the system is failing them.

And so I think part of what we are doing at the March of Dimes is acknowledging and working with many partners to say what can we do as one participant in the system to change these kinds of outcomes and to help the system realize that there is implicit bias in the system that medical providers, though they don't intend to, are making judgments about Black women and are then therefore causing Black women to receive inadequate care, often putting their lives at risk.

And so part of what we are doing, just one of the things that we are doing is, in addition to have entire health equity approach to our work, is looking at certain programs like introducing an implicit bias program. Dr. Crear-Perry talked about the work she is doing in that space. We have worked with an organization to create a whole new implicit bias program for many of our hospital and other health care provider partners to make sure that they are aware of the implicit bias that they may be experiencing on a daily basis, that it is actually influencing the lives of the patients that are attempting to serve.

Ms. UNDERWOOD. Yeah, putting their lives at risk.

Ms. STEWART. Absolutely.

Ms. UNDERWOOD. Earlier this month the Commonwealth Fund published a report showing that the Affordable Care Act narrowed racial and ethnic disparities in insurance coverage. And we know that in the context of today's hearing, coverage leads to better outcomes for moms and babies, and yet as we speak the Affordable Care Act is being threatened by a Republican repeal lawsuit.

Ms. Stewart, what is at stake with this reckless attack on health care and how could it exacerbate existing racial and ethnic disparities and maternal and infant health outcomes?

Ms. STEWART. So we know that the ACA has been an incredible support to expanding coverage for so many women. And it is especially true for women of color, where their rate of women that have qualified under ACA has grown at more than twice the rate of women overall between the period of 2013 and 2015. And what this has been doing is allowing women to access the care they need.

Again, to talk about this issue is really to underscore the importance of women getting the kind of preventive care they need before pregnancy and during pregnancy. The fact that they now—many of these women, women of color, have more access to the kinds of coverage that is available to the ACA, especially because of essential health benefits being involved.

Ms. UNDERWOOD. Yes.

Ms. STEWART. So no cost sharing applied to all kinds of well women visits, all kinds of prenatal care visits that are really essential and incredibly important. You know, we still look at prenatal care visits and still know that too many women are not able to access the kind of prenatal care that they need. If ACA is removed, if they don't have access to being able to get the kind of health coverage that the ACA provides for women, especially women of color, we are likely to see a worsening of outcomes for those women and a worsening of outcomes for their babies. It simply would be devastating to so many of the families that we are trying to serve.

Ms. UNDERWOOD. Thank you.

Madam Chair, my time is expired. I could sit here all day and talk about this issue. It is so important. Thank you for your leadership and for convening us here today. Thank you to the witnesses, and thank you for being a member of the Black Maternal Health Caucus.

Chairwoman WILSON. Thank you.

Dr. Shalala.

Ms. SHALALA. Thank you very much, Madam Chair. Let me congratulate Representative Adams and Underwood for their leadership of the Black Maternal Health Caucus. Those of us that joined it, we have a simple goal, save Black women's lives and tackle racial disparities in health care.

My colleague from Florida has already indicated the statistics in our own Miami-Dade County, which the racial disparities are simply criminal and not acceptable. But the root cause of the statistics for maternal death are often misunderstood. The public image of maternal death is a woman who has a medical emergency, like a hemorrhage, while in labor, rather than four out of five of these deaths happen in the weeks and months before or after birth. And ensuring women have access to comprehensive and affordable care during and after pregnancy is absolutely critical.

I do want to put on the record that over 96 percent of Planned Parenthood services are really in women's health. It is to help women be and stay health before, after, and between pregnancies. And Planned Parenthood does not, unlike the myths, make money on abortions. Planned Parenthood is supported by charity and by contributions from millions of Americans.

I want to ask a very specific question, because what I am interested in is in Federal programs. We have talked a bit about Federal programs and about filling in the gaps. We know that chronic medical conditions, including obesity, cardiovascular disease, hypertension are chief contributors to maternal mortality, yet we have also heard that Federal programs are not designed to support women's overall health before and in between pregnancies. Medicaid's pregnancy coverage only extends to 60 days of postpartum, WIC's postpartum coverage only covers 1 year for breastfeeding

women, and the ACA has real limitations, including those that were pointed out on women under 26. If we are going to write a comprehensive bill here, it is really going to be a bill that fills the gaps while we are waiting for universal seamless health coverage that would make a difference for all Americans.

So I would like to ask each of you what your top two or three recommendations would be, specifically on program supports and program improvements, because what we might do is simply go through all the programs and do a comprehensive bill that fills in the gaps on the programs. That would be I think a lifesaving step for all of us.

Let us start with Ms. Stewart.

Ms. STEWART. So I guess a couple of things I will mention. I think one of the most important things that can be done is the extension and expansion of Medicaid up to 1 year. I think the fact that we have too many women that are being dropped from coverage within 60 days to several months after childbirth is a real challenge. And it is inhibiting their ability to seek the kind of continued medical care that they need.

A couple of other things that I will mention though. I think it is really important to look at what Medicaid covers beyond just the medical care for the health care provider. We know that access to Medicaid reimbursement for doulas, for midwifes, and I would even say—we are involved in a program that is involving group prenatal care. That is an evidence-based program and it is shown to reduce the rate of preterm birth by up to 30 percent. But in many states we are not able to receive Medicaid reimbursement. But we know that is the kind of care that women often need beyond just their traditional health care. So there are things like that.

And the last thing I will just mention is we do have some gaps and some barriers, for example, around newborns being added to health plans. We find that they are too many families who have a 30-day window to add their newborn to a health plan and often miss that window. And then as a result, especially if their baby is in the NICU, they may be subject to exorbitant health care costs because they missed that window. And so closing that gap would be also very important.

Dr. CREAR-PERRY. So I will go by agency. So HRSA, you could improve how we do National Healthy Start. It is a great program, it is community led, community driven. CDC, we can bolster up the PQC, the Perinatal Quality Collaboratives. They are the driving force of how we are going to get policy done. We have not invested in those. And then in the NIH, you can uplift the Office of Women's Health. It is just an office, so it has no budget. So we think women are more than half of the population and yet we don't have any dedicated institute or center for women's health. So it would be exciting to see you all look at these big larger institutions and how you could change them.

I mean really investing in community birth workers on the ground, lay folks who have been doing the work for the community for a long time. I mean the education policy, we wanted an education plan. Black maternal health week is coming up, so there will be a lot of investment—April 11–17—looking all the folks on the ground who are doing work.

Ms. SHALALA. Thank you.

Chairwoman WILSON. Thank you very much.

Mr. Levin from Michigan.

Mr. LEVIN. Thank you very much, Madam Chairwoman.

It is an honor to be here with the Chairwomen of these subcommittees, with Congresswoman Underwood. I thank her for her leadership. And with all three of you to talk about this incredibly important issue.

It is simply outrageous and unacceptable that so many women and babies of color die at disproportionate rates in this country. And we need to be able to talk about racism in this country. I want all of my White siblings in spirit who may be freaked out if I can just speak plainly about being called a racist, or worried that they might be whenever we talk about racism. Look at this situation. This is structural racism. In our society, when people like Congresswoman Underwood's friend die, who have every advantage in life, there is no explanation but structural racism. So let us all take a deep breath, relax our shoulders, and get on with the conversation. Because we just commemorated Holocaust Remembrance Day and we say never again, and what does it mean. It means we must not be silent in the face of injustice. This is clear injustice in our society and we all have a role to play and none of us can be silent.

Now, Dr. Crear-Perry, I am worried I am going to get in trouble with you. I was not planning on raising this, but I think your very first answer to a question was about midwives. So I have four kids and we had home births with midwives, but it was not legal in Maryland. So we had illegal home births with the lay midwife. So here I am confessing. Koby was born 26 years ago.

Mr. SCOTT. Statute of limitations.

Mr. LEVIN. Yeah, I hope so, Mr. Chairman. And at the same time I am I think the only member of this body who has run a state workforce system. So I feel personally responsible for—so talk to me about the training at, you know, HBCUs, at other institutions. What do we need to do to train more midwives? Because it is certainly a crucial part of the answer here.

Dr. CREAR-PERRY. Thank you. In the same way that you want our colleagues to not have their shoulders raised when we talk about racism, which is what I have to do a lot with folks, I have to have my colleagues in OB/GYN not have their shoulders raised when we talk about midwifery.

Mr. LEVIN. That is why I thought I might get in trouble.

Dr. CREAR-PERRY. No, no, actually my shoulders are relaxed, I am good. Because I don't feel threatened. We need this. Every country that has better outcomes than us has a much more robust midwifery workforce. They have invested in training women across the country who actually are doing the births. We provide care in an ICU that could be done, like you did, at home. And that is just a fact. And we are afraid of change, but that fear is harming Black women. And actually Black women are over performing their counterparts when it comes to home birth and not having a hospital birth because of our fear. Imagine going into Auschwitz without Auschwitz ever having apologized and saying you are now supposed to take care of me and provide my health care. That is what happens to Black women when we go to the hospital, the same hos-

pitals that for generations harmed us now are saying come, we are fine now, with never having acknowledge J. Marion Sims, never having acknowledged the history of oppression, and we are just supposed to trust you because you are nice.

Mr. LEVIN. All right. So I am going to count on you to follow up with me as a member of this committee, so what specifically can I do on that.

Dr. CREAR-PERRY. Yes. Right. Thank you.

Mr. LEVIN. Ms. Sankofa, protections entitling nursing workers to have break time and a private space, right, it is tied to nursing a child and lasts only for a year following the birth of a child. So in my last minute I want to ask you, should we rethink these policies? For example, a woman may be lactating after her baby has been adopted. You know, for her health, shouldn't she have coverage? After a stillbirth. The time limit. I mean my wife breastfed way past 1 year. So are these limits too narrow and inappropriate?

Ms. SANKOFA. I think that these limits are put in place to really create an opportunity to have deep buy in from all members so that we can move the legislation forward. But when we look at preterm birth weights, when we look at infant mortality rates, I think that a person who is pumping to provide milk for a baby who is not their own but who may be preterm, I think that is something very, very important to consider as a more systemic policy solution because not every woman chooses to breastfeed, maybe there are systemic barriers for her that make it unavailable. But if milk can still be available, that is a thing that we should definitely consider.

Mr. LEVIN. Outstanding. Thank you.

I yield back, Madam Chairwoman.

Chairwoman WILSON. Thank you so much, Mr. Levin.

Ms. Stevens.

Ms. STEVENS. Thank you, Madam Chair, and thank you to our expert witnesses for your brilliant and elucidating testimony and for your comments here today.

We have an emergency going on in America right now. The U.S. has the worst maternal mortality rate among developed countries despite an improvement in global maternal mortality. This is what we are talking about here today, this is what this conversation is about. From the halls of the United States House of Representatives, I can't think of a more important topic because for every woman that has lost their life, for every family bearing that burden, for every woman who has come too close to losing her life, crying out in pain, this is senseless and these are injustices. And we talk about life being precious. I cannot think of a better instance of the sanctity and preciousness of life than this, than the life of the mother. We are here for the voiceless.

Thank you, Ms. Underwood, for your leadership in forming the Black Maternal Mortality Caucus, because it is high time for these issues to come to bear, it is high time for this to be on the national news and in every family's household, thinking and talking about this and what we are going to do. Thank you, ladies for your leadership.

Ms. Stewart, you represent a phenomenal organization. It is in every community's hearts and in our states and it is on our mind. And we know about 1 in 33 children born in the United States is

born with an anomaly, a congenital anomaly. And, you know, they are required to go through various surgeries on occasion. We are thinking about the cleft palates.

Could you just describe some of these challenges that families face in affording this important care? And also legislation that I am a proud co-sponsor of, the Ensuring Lasting Smiles Act, and how that would maybe make a difference, Ms. Stewart.

Ms. STEWART. Sure. Thank you for that.

Ms. STEVENS. Thank you.

Ms. STEWART. And we agree with all of your comments.

Ms. STEVENS. Thank you for your leadership.

Ms. STEWART. You know, this is really an important issue that often doesn't get discussed. And we talk a lot about maternal deaths and infant deaths. We don't often talk about when a pregnancy doesn't go as expected, the long-lasting health impacts that a child has to deal with and what families often have to deal with.

And one of the things that is really a big challenge for too many families in this country are the number of children that are born with these kind of congenital anomalies or birth defects. And about 4 percent of all the children in the U.S. are born with these birth defects. Again, the March of Dimes has spent a lot of our history trying to deal with eliminating birth defects through encouraging women, for example, to take folic acid to deal with preventing certain birth defects.

But the Ensuring Lasting Smiles Act is really a piece of legislation that we support strongly, with about 30 other organizations. Right now what it is intended to do is ensure that all private group and individual health plans cover medical necessary services. And what we know is that there are many plans that do actually provide for coverage for medically necessary surgeries and other kinds of treatments that should be made available to children that are born with these kind of birth defects. But we are hearing that there are too many instances in which some coverage is denied, often because insurance companies will claim that a certain kind of surgery, especially dental surgeries is where this happens a lot, are more cosmetic in nature when we know in fact a baby that is born with a cleft palate, for example, will have extreme difficulties with breathing or eating and really living a normal life.

And so what we are trying to do with this legislation, and ask you all to do, is consider the fact that there should not be any family that is denied coverage or having to assume too much in terms of cost and to make sure these kind of services are available.

Thank you.

Ms. STEVENS. Well, thank you for that. Your leadership has been phenomenal.

Madam Chair, I have a letter to submit for the record from the National Foundation for Ectodermal Dysplasias.

And with my remaining time I would like to just get one more question and cede my time to Congresswoman Underwood.

Ms. UNDERWOOD. Thank you, Congresswoman Stevens.

Ms. Sankofa submitted an excellent written testimony that spoke about the PUMP for Nursing Mothers Act, a bill that fixes a legal glitch that currently prevents millions of middle class moms from reentering the workforce after giving birth.

Madam Chair, I would like to ask unanimous consent to submit for the record a letter from more than 100 organizations endorsing the PUMP for Nursing Mother's Act.

Chairwoman WILSON. Without objection.

Ms. UNDERWOOD. Thank you, Madam Chair. And thank you, Ms. Stevens.

And I yield back.

Ms. STEVENS. I yield back the remainder of my time.

Chairwoman WILSON. Mr. Scott, Chairman Scott.

Mr. SCOTT. Thank you. Ms. Stewart, it is good to see you again.

Ms. STEWART. Good to see you.

Mr. SCOTT. Many of the witnesses talked about the substantial number of deaths that are preventable. Can you describe the ultimate cost to the health care system of the initiatives that would prevent many of these deaths?

Ms. STEWART. So according to the CDC, about three out of every five of these deaths are preventable. A lot of the deaths that see as preventable are often due to misdiagnoses or delayed diagnoses and a lack of adequate care that is being provided to those women.

One of the things—I don't have the exact numbers—I can get you the exact numbers, but one of the things that could be very helpful is when women show up at a hospital, for example, to deliver their baby, there should be the proper protocols in place. And some of those protocols come from something that Dr. Crear-Perry mentioned, which are the AIM bundles that ACOG and others have been promoting, and that is to ensure that hospitals have these improved bundles of care, protocols of care, that would prevent these kinds of deaths from happening.

So, for example, when a woman is hemorrhaging, how do you deal with hemorrhage and how do you deal with it in labor and delivery when that typically hasn't been a place where you have seen a lot of hemorrhage. How can you change practices so those kinds of deaths are prevented?

There are probably some dollar amounts attached to it and we can follow up and get you that, but I do think that those are some of the things that are important.

Mr. SCOTT. Well, things like doulas, have you studied those to see whether they save more money than they cost?

Ms. STEWART. Absolutely. There have been studies that show that doulas and midwives, but especially doulas, can reduce and prevent unnecessary maternal deaths, can actually improve birth outcomes, can actually make sure that mothers are safer and have healthier pregnancies.

Mr. SCOTT. And a lot of the provision of prenatal care will reduce the incidence of low birth weight and ultimately save more money than it costs?

Ms. STEWART. Prenatal care and then I think what we ought to look at is in places that we have looked at the March of Dimes, these maternal care deserts where there isn't traditional prenatal care, how can things like telemedicine and other kinds of services be made available. And those are some of the gaps that we see that should be addressed.

Mr. SCOTT. Now, do you have data that show that the prevention initiatives actually work?

Ms. STEWART. We do. I mentioned one earlier. In addition to some of the studies I've referenced around doulas, some of the areas around group prenatal care are evidence-based, have been shown to reduce preterm birth by 33 percent. So we know that has a measurable impact in improving lives and saving lives and producing better health outcomes as well.

Mr. SCOTT. And what kind of initiatives before pregnancy—you mentioned folic acid—before pregnancy and after birth, what kind of initiatives can be helpful?

Ms. STEWART. So I think a couple of things. One is that really adequate good prenatal care is really important. But what I would say is even before pregnancy a woman has to be able to be as healthy as possible. One of the things that we are seeing that really is affecting some of these outcomes is that women go into pregnancy with many more chronic health challenges than existed in the past. So having a woman being able to have the health coverage that she needs to address obesity challenges, hypertension challenges that she may be having so that she improves her health before she is pregnant we know can have measurable impact. As well as support that she may need in the postpartum period, especially around not only her physical health, but also her mental health as well. And that mental health coverage needs to be available throughout her period of time before, during, and after pregnancy.

Mr. SCOTT. Thank you.

Dr. Crear-Perry, my colleague, Representative McBath, mentioned the Family Violence Prevention Services Act is also in this committee. Can you talk about the Federal services that could be provided that would have the effect of reducing violence and how that would reduce maternal deaths?

Dr. CREAR-PERRY. So we have a real gap when it comes to intimate partner violence as far as policies. Places for people to go if they are in danger, so providing support for cities like my own of New Orleans, to have housing and have an availability for victims of domestic violence would be really important. Having policies that allow for safety for moms inside of workplaces. Those are all really important. So there is a direct tie between the elevated risk that someone has in the world when they are pregnant, when it comes to intimate partner violence and the ability to mitigate that risk through Federal legislation.

Mr. SCOTT. Thank you, Madam Chair. I yield back.

Chairwoman WILSON. Thank you, Mr. Scott.

Ms. Bonamici.

Ms. BONAMICI. Thank you, Madam Chair. I really appreciate this conversation. Thank you to our witnesses for your expertise. I think it has been a difficult but very important conversation to hear that we are regressing as a country when it comes to maternal and infant health. The wellbeing of mothers and babies are sort of fundamental measures of any nation's development. And to many Americans I think the statistics that we have heard today might sound like they are coming from a different country or a different time. But it is a reality that we have to face, so we must—we must—face it, we must address the failings and improve outcomes for all families.

And we touched on several policies, particularly I want to point out the inexcusably stark disparities for racial minorities.

I would like to emphasize the point made by several of the witnesses, that we can improve the likelihood of health births even before pregnancy. Access to comprehensive reproductive health, including contraception and prenatal care empowers women to make decisions about when and in what circumstances they choose to become pregnant.

I am currently working to update legislation. I introduced last session the EQUIP Act that will encourage health care providers to routinely ask women of childbearing age about their intentions regarding pregnancy and to provide appropriate care in response to those conversations. March of Dimes was one of the organizations that endorsed the legislation because these pregnancy intention screenings improve the likelihood of healthy births. It is kind of a win-win because it is good for maternal health and it also reduces unintended pregnancies.

And some of you might have noted that Oregon was the only state that has got an A- in the March of Dimes report. In all fairness, we don't have a lot of racial diversity, but we also have many clinics that are using the sort of One Key Question, pregnancy intention screening, and we also sort of aggressively expanded Medicaid, we have coordinated care organizations. So we are doing a good job in many ways, but there is still a lot of work to do. We have to make sure that we are addressing those implicit biases.

Dr. Crear-Perry, you spoke about positive health outcomes being dependent on implementation of all sexual and reproductive rights. Can you talk about how those rights might not be respected in health care setting pre-pregnancy and how policies can take that into account?

Dr. CREAR-PERRY. So I usually, when I am doing data, I point out that although the United States is the worst in the world when it comes to maternal mortality and Black women are dying at three to four times the rate, that also means a lot of White women are dying that should not. And places like Oregon give us an example of what we could do better as a country if we invested in everyone and invested in things like insurance and other things. So it is important for us to think about when you restrict access to contraception—so we have data—my colleague Maeve Wallace and others, the places that have more restrictions on access to contraception have the worst outcomes for maternal and child health.

Ms. BONAMICI. Right.

Dr. CREAR-PERRY. So when they say language around we are making things safer for moms, you are actually making things worse. So the data is the opposite of this narrative around safety. So restrictions for sex education causes harm, causes death.

Ms. BONAMICI. Absolutely.

Dr. CREAR-PERRY. Restrictions for access to birth control, for LARCs, for abortions. All those things cause harm and cause death. The more you put policies in place that are barriers, they more that women and children are more likely to die.

Ms. BONAMICI. Right. Our legislature on a bipartisan basis passed legislation to fill contraception prescriptions for whole year rather than short-term, which my daughter really appreciates.

Dr. CREAR-PERRY. Right. Yes.

Ms. BONAMICI. So I recently visited a WIC clinic in Washington County, Oregon and saw firsthand how important these services are for women and families who want to give their children a healthy start in life.

I just want to mention, in light of the public charge opinion from the Supreme Court yesterday, I think we are going to see more and more families afraid to reach out for services. But WIC serves almost 15,000 people county-wide, 79 percent of clients are working families and 22 percent are pregnant. We know that this nutrition education, and connection is beneficial in terms of improving birth weights and reduction in premature births and fewer infant deaths.

Ms. Stewart, studies continue to confirm WIC's role in reducing the likelihood of preterm birth. Only a slight majority of pregnant WIC recipients, just a little more than 53 percent, are certified for the program in their first trimester. Do you know why this is? And what can we do to better encourage certification of pregnant women?

Ms. STEWART. I think a lot of people are very shocked when they find out how important WIC is in terms of serving pregnant and postpartum women, infants, and children younger than the age of five. Almost half of the 4 million babies that are born in the U.S. have been able to access WIC. And so it is an important program.

We do think that having more access and having more community workers and community access to make sure that women understand how to overcome the barriers—

Ms. BONAMICI. Right.

Ms. STEWART.—to become eligible for WIC is really important. WIC has proven to be one of the most effective evidence—based programs to ensure that, to your point, we can improve health outcomes, reduce infant mortality, reduce risk of preterm birth. We are strong in favor of expanding and improving access and looking at ways in which to improve those community access points as well.

Ms. BONAMICI. Thank you. And I see my time has expired.

I just want to say how important paid family leave is. That we are the only industrialized country to not have paid family leave and what a difference it makes. My state at the state level passed paid family leave, but we absolutely must, as a country—it is shocking that so many women go back to work within just a couple of weeks. I was fortunate. With my first child I was able to take 6 months off. Most women can't do that. And I still, you know, had to explain to people why I needed to take a break to go pump in the restroom. And so, you know, having paid leave really makes a difference for a healthy start for children and families.

And I have gone over my time, so I yield back, Madam Chair. Thank you very much.

Chairwoman WILSON. Chairman Scott? Ms. Underwood?

Ms. UNDERWOOD. Thank you, Madam Chair.

I request unanimous consent to submit a written testimony from the American College of Obstetricians and Gynecologists for the record.

Chairwoman WILSON. Without objection.

Ms. UNDERWOOD. Okay. Thank you so much.

Chairwoman WILSON. Mr. Scott

Mr. SCOTT. And, Madam Chair, I ask unanimous consent to introduce into the record a report from the Institute for Gender and Culture of the Black Women's Blueprint entitled "The Sexual Abuse to Maternal Mortality Pipeline".

Chairwoman WILSON. Without objection.

I remind my colleagues that pursuant to committee practice, materials for submission for the hearing record must be submitted to the Committee Clerk within 14 days following the last day of the hearing, preferably in Microsoft Word format. The materials submitted must address the subject matter of the hearing. Only a member of the committee or an invited witness may submit materials for inclusion in the hearing record. Documents are limited to 50 pages each. Documents longer than 50 pages will be incorporated into the record by way of an internet link that you must provide to the Committee Clerk within the required timeframe. But please recognize that years from now that link may no longer work.

Again, I want to thank the dynamic witnesses for their participation today. What we have heard is very valuable. Members of the committee may have some additional questions for you and we ask the witnesses to please respond to those questions in writing. The hearing record will be held open for 14 days in order to receive those responses.

I remind my colleagues that pursuant to committee practice, witness questions for the hearing record must be submitted to the majority committee staff or Committee Clerk within 7 days. The questions submitted must address the subject matter of the hearing.

I now recognize Workforce Protections Chair Adams for her closing statement.

Ms. ADAMS. Thank you, Madam Chair. I want to join you in thanking Ms. Stewart, Ms. Sankofa, and Dr. Crear-Perry for their compelling testimony today. I also want to thank my colleagues for coming together for this bipartisan hearing.

Today's discussions confirmed what mothers and communities across the country have long known, our Nation's maternal and infant health is in crisis and the Federal government must do more to stop it. And to that end we must advance proposals that address disparities in maternal and infant health and expand access to health care and nutrition.

Further, we must ensure that our Nation's workplaces provide critical supports, like designated pumping breaks for pregnant workers and new mothers.

In closing, I am grateful that we could reaffirm today that maternal and infant health are not partisan issues and each of us here agrees that we have a shared responsibility to serve our constituents by supporting affordable quality maternal and infant care.

I look forward to working with my colleagues to ensure that any mother anywhere in the United States can receive the quality care and support she needs to navigate a healthy pregnancy and raise a healthy child. I am a mother and I am a grandmother, and so I look forward to having some great grandchildren one day.

But before I yield, I would like to enter into the record a statement from the organization A Better Balance in support of today's

hearing and Federal solutions to improving maternal and infant health outcomes among women of color.

Chairwoman WILSON. Without objection.

Ms. ADAMS. Thank you. I now yield to my esteemed colleague and Chair of the Subcommittee on Health, Employment, Labor, and Pensions, Frederica Wilson, for a closing statement. And thank you very much, Madam Chair, for bringing us together.

I yield back.

Chairwoman WILSON. I now recognize HELP Ranking Member Walberg for his closing statement.

Mr. WALBERG. Thank you, Madam Chairwomen, for this hearing and thank you to the panel for being here.

And I agree, Madam Chairwoman, that this indicates and shows that this is not a partisan issue, this is a bipartisan issue of concern.

Now, we may not agree on every point. I think you understand that. I think a lot of what we teach out there is caught, not taught, by verbs and nouns, pronouns, statements. And so I can never—I can never support the fact that abortion is a good choice for a woman or a child or society because it again reduces the value of a human life itself. And I understand there is a disagreement on that.

I have a concern about any type of support for intimate partnership. That term. As a man that says to me I don't have to make a commitment that is lasting. I did not educate to my sons that way. I am so thankful my son in law was not educated that way either. And we can disagree on that.

But there are a lot of things we can agree on and move forward. Certainly I was glad to support funding and continue to support funding for Federally qualified community health centers. I have a number in my seven-county district that do excellent work and provide services that families and individuals wouldn't get otherwise. I can see supporting extension of Medicaid for mothers and children after birth through a legitimate realistic and important period of time to make sure that we deal with those issues of concern. I certainly can see that.

So I guess I would end, Madam Chairwoman, and all those who are interested here today, that there are some things we can agree on to make a pact for. I wrote a few things down. There could be more. But let us make a pact to love all babies beginning at conception, let us make a pact to love and support mothers and motherhood. I hope you see the difference. It is special. Let us make a pact to push fathers to do all and anything they can to protect and care for their children and the mother of their children. Let us make a pact to do that. Let us make a pact to motivate all agencies and policy makers to implement science and research- based lifesaving procedures and policies promoting birth and maternal health. And let us make a pact to promote the family structure that fosters positive maternal and infant health and functional families. And let us make a pact to say you can't have everything without sacrifice, so make sure that we promote an understanding of the sacrifice that it takes in each individual situation and person to ultimately come to the end result of promoting quality maternal

and infant health and the continuation through their whole lifetime.

Thank you. And with that, I yield back.

Chairwoman WILSON. Thank you, Mr. Walberg.

I now recognize myself for a closing statement.

I want to add my appreciation to the wonderful witnesses for taking the time to be with us today. You were phenomenal. We have many, many hearings—many—every day and you are a panel that I would rate A+. Thank you so much.

The United States is home to some of the best medical care in the world. People come here from across the globe seeking medical treatment they cannot otherwise access. Yet each year tens of thousands of mothers across the country, particularly Black and Brown mothers, cannot access the quality care they need to have healthy pregnancies.

As our witnesses made clear, these mothers face barriers to securing proven government services and quality health care. They face severe gaps in coverage that restrict access to care and they face systemic discrimination and racism throughout our health care system. For too long the Federal government has done too little to address these complex issues. As a result, our Nation's maternal and infant health is falling behind the rest of the world.

The time to act is now. This Congress we have a bipartisan opportunity to fight the maternal and infant health crisis together. We can and must pass legislation that follows research and evidence, supports proven Federal services, and expands access to quality health care for all mothers.

Moving ahead, I look forward to working with my colleagues on both sides of aisle. And I am just happy to hear what they said today, to advance proposals that achieve those shared goals. If we work together, we can succeed in delivering for the mothers, the infants, the communities, and the future of our country.

If there is no further business, without objection, this committee stands adjourned.

[Additional submission by Chairwoman Adams follows:]

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the work and family legal center

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Statement of Dina Bakst
Co-Founder & Co-President
A Better Balance

House Committee on Education & Labor
Subcommittees on Health, Employment, Labor, and Pensions Subcommittee & Workforce Protections
"Expecting More: Addressing America's Maternal and Infant Health Crisis"
January 28, 2020

Thank you to Chair Adams, Chair Wilson, Ranking Member Byrne, and Ranking Member Walberg for the opportunity to submit a statement to the Subcommittees on Health, Employment, Labor, and Pensions Subcommittee & Workforce Protections for today's hearing, "Expecting More: Addressing America's Maternal and Infant Health Crisis." A Better Balance is a national non-profit legal organization that advocates for women and families so they can care for themselves and their loved ones without sacrificing their financial security.

As today's hearing suggests, there are myriad factors contributing to this nation's current maternal and infant health crisis, a crisis that is disproportionately impacting Black women and women of color.[i] As a workers' rights organization, we believe one key piece of the solution to this crisis, among many, is the need to ensure our workplaces are safe and supportive environments for pregnant workers and mothers.

Unfortunately, the reality is that too many pregnant women, especially women in low-wage and physically demanding jobs who are largely women of color, are forced to risk their health at work. Since our founding, we have heard from hundreds of women across the country whose employers either fired or forced them onto unpaid leave when they requested modest, temporary job adjustments to remain healthy and on the job or needed access to break time and space to express milk at work.[ii]

As we see up close through our free legal helpline and direct services work—especially in our Southern Office—this failure to accommodate pregnancy and the need to express milk often results in devastating health consequences for working women and their families.[iii] In a recent health impact assessment conducted by the Louisville, Kentucky Department of Public Health and Wellness, the agency found that "Accommodating pregnant workers, upon their request, is critical for reducing poor health outcomes . . . . Improving birth outcomes makes a sustainable impact for a lifetime of better health."[iv] The study went on to highlight that poor outcomes from a failure to receive accommodations can include "miscarriage, preterm birth, low birth weight, preeclampsia, and birth defects, among other issues."[v]

Improving health outcomes is especially crucial in the South where preterm birth rates are abysmal–in its 2019 report card, the March of Dimes gave "F" rankings only to Southern states,

including Alabama, Mississippi, and Georgia.[vi] Tennessee and Kentucky were not far ahead, earning "D" grades.[vii]

Such outcomes may be prevented with modest workplace accommodations.[viii] For instance, a reduction in lifting can help "avoid preterm births and miscarriages."[ix] Because federal law does not provide an explicit right to reasonable accommodations, too many workers are forced to continue risking their health by working without these accommodations. Women of color are especially impacted as they are more likely to work in low-wage, physically demanding jobs.[x]

The Pregnant Workers Fairness Act (H.R. 2694), which passed with bipartisan support out of the House Education and Labor Committee on January 14, 2020 is one crucial step Congress must enact in order to reduce these disparities and ensure that all pregnant workers, and especially women of color, can remain safe and healthy at work no matter their zip code. The measure requires employers to provide reasonable pregnancy accommodations unless it would impose an undue hardship on the employer.

Twenty-seven states and five cities already have these protections in place and we have begun to see the positive effects such laws can have on women's lives.[xi] For instance, Takirah Woods, a woman of color, worked in family services for a state agency and lives in a state with a pregnant workers fairness law. When she became pregnant in 2018, her doctor advised her not to lift over 15 pounds. When HR found out about her restriction they pushed her out onto unpaid leave. Needing her paycheck, Takirah pleaded with her doctor to lift the restriction even though it could compromise her health. However, after learning about the pregnancy accommodation law in her state and contacting A Better Balance, the employer reinstated her just two weeks later and provided her with a light duty accommodation through the rest of her pregnancy. However, women in states without such laws are forced to risk their health every day – the Pregnant Workers Fairness Act would ensure no woman is forced to choose between her job and her health.

Congress must also strengthen our laws to support breastfeeding workers. While the federal Break Time for Nursing Mothers Law requires employers to provide reasonable break time and space to express milk, an unintentional gap in the law has left millions of women without federal protections. The benefits of breastfeeding for both mother and infant are well documented. According to the surgeon general, breastfeeding reduces the risk of sudden infant death syndrome as well as other infant illnesses, and breastfed infants are "less likely to develop asthma" and become obese.[xii] For mothers, breastfeeding can, among other benefits, lead to a "decreased risk of breast and ovarian cancers."[xiii] Given that more than half of women return to work within three months of giving birth, and medical providers recommend breastfeeding through a baby's first year of life, it is crucial that women be able to have the time and space to adequately express milk.

The PUMP Act (H.R. 5592) would close the gap in the 2010 law that is currently excluding 9 million employees from coverage as well as provide clarity as to when this break time must be paid or can be unpaid, and provide nursing mothers the ability to access remedies if their rights are violated under the law. Congress must work swiftly to pass this measure into law.

Finally, Congress must pass other key workplace protections that support the health, wellbeing, and economic security of working mothers and families including the **FAMILY Act (H.R. 1185)** which would provide families with 12 weeks of paid family and medical leave to bond with a new child, care for a loved one with a serious health condition, or attend to one's own serious medical needs, and the **Healthy Families Act (H.R. 1784)**, which would provide workers with up to 56 hours a year of paid sick time to care for loved ones with illnesses or injuries. As of 2018, an estimated 26 percent of workers nationwide did not have access to a single day of paid sick time.[xiv] Women—especially women of color—are overrepresented in low-wage industries where workers have no paid sick days and are often fired or not paid for absences.[xv] More than half of Latina workers and 36 percent of Black women workers do not have access to paid sick days.[xvi] This means women of color who may be pregnant or recently welcomed a new child lack the ability to address their pre- or post-natal medical needs such as attending prenatal appointments or infant checkups.

Women in the United States now make up more than half of the workforce[xvii] and three-quarters of women will be both pregnant and employed at some point in their working lives.[xviii] But our workplaces and work cultures too often remain unsafe and hostile to women and mothers, especially women of color. Congress must enact workplace policies like the Pregnant Workers Fairness Act, the PUMP Act, the FAMILY Act, and the Healthy Families Act that harmonize work and childbearing — our mothers and babies lives depend on it.

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[i] *See* SUNSHINE MUSE, BLACK MAMAS MATTER ALLIANCE, SETTING THE STANDARD FOR HOLISTIC CARE OF AND FOR BLACK WOMEN 3 (Apr. 2018) (citing CTRS. FOR DISEASE CONTROL AND PREVENTION, HEALTH UNITED STATES, 2016: Table 10, INFANT, NEONATAL, POST-NEONATAL, FETAL, AND PERINATAL MORTALITY RATES, BY DETAILED RACE AND HISPANIC ORIGIN OF MOTHER: UNITED STATES, SELECTED YEARS 1983–2014 (2016)), https://www.cdc.gov/nchs/data/hus/2016/010.pdf), http://blackmamasmatter.org/wp-content/uploads/2018/04/BMMA_BlackPaper_April-2018. pdf; *see also* Linda Villarosa, *Why America's Black Mothers and Babies are in a Life-or-Death Crisis*, N.Y. TIMES, Apr. 11, 2018, https://www.nytimes.com/2018/04/11/magazine/black-mothers-babies-death-maternal-mortality.html.

[ii] For a snapshot of these workers' stories, see A Better Balance, *The Women Who Inspired the Movement for the Pregnant Workers Fairness Act, https://www.abetterbalance.org/resources/the-women-who-inspired-the-movement-for-the-pregnant-workers-fairness-act/* (last updated on Jan. 13, 2020).

[iii] *See* Jessica Silver-Greenberg & Natalie Kitroeff, *Miscarrying at Work: The Physical Toll of Pregnancy Discrimination*, N.Y. TIMES, Oct. 21, 2018, https://www.nytimes.com/interactive/2018/10/21/business/pregnancy-discrimination-miscarriages.html (highlighting A Better Balance client Tasha Murrell who miscarried while working at a warehouse in Tennessee after her manager denied her medically-advised lifting restriction).

[iv] LOUISVILLE DEP'T OF PUBLIC HEALTH AND WELLNESS, PREGNANT WORKERS HEALTH IMPACT ASSESSMENT 2019, at 7 (2019), https://louisvilleky.gov/sites/default/files/health_and_wellness/che/pregnant_workers_hia_final_02182019.pdf.

[v] *Id.*

[vi] *2019 March of Dimes Report Card*, MARCH OF DIMES, https://www.marchofdimes.org/mission/reportcard.aspx

[vii] *Id.*

[viii] LOUISVILLE DEP'T OF PUBLIC HEALTH AND WELLNESS, SUMMARY OF THE PREGNANT WORKERS HEALTH IMPACT ASSESSMENT (2019), https://louisvilleky.gov/sites/default/files/health_and_wellness/che/pregnant_workers_hia_one_pager.pdf.
[ix] *Id.*
[x] See A Better Balance & Nat'l Women's Law Ctr., It Shouldn't Be A Heavy Lift: Fair Treatment for Pregnant Workers 11 (2013), https://www.abetterbalance.org/resources/it-shouldnt-be-a-heavy-lift/.
[xi] A BETTER BALANCE, PREGNANCY ACCOMMODATIONS IN STATES & CITIES (2019), https://www.abetterbalance.org/wp-content/uploads/2019/01/PWFA_StateList.pdf.
[xii] Office of the Surgeon General, *Breastfeeding: Surgeon General's Call to Action Fact Sheet* https://www.hhs.gov/surgeongeneral/reports-and-publications/breastfeeding/factsheet/index.html.
[xiii] *Id.*
[xiv] U.S. BUREAU OF LAB. STATISTICS, *Nat'l Compensation Survey, March 2018,* "Table 32. Leave benefits: Access, civilian workers" (March 2018), https://www.bls.gov/ncs/ebs/benefits/2018/ownership/civilian/table32a.pdf. The BLS does not collect data on paid safe time access, but the percentage of workers who have access to safe time is *substantially* lower than the percentage of workers with access to sick time.
[xv] Women are nearly two-thirds of minimum-wage workers, and the vast majority of women earning minimum wages receive *zero* paid sick days. *See* THE SHRIVER REPORT, "Facts and Figures from The Shriver Report: A Woman's Nation Pushes Back from the Brink" (Jan. 12, 2014) [hereinafter THE SHRIVER REPORT], http://shriverreport.org/a-womans-nation-pushes-back-from-the-brink-facts-and-figures.
[xvi] INST. FOR WOMEN'S POL'Y RESEARCH, *Briefing Paper: Paid Sick Days Access and Usage Rates Vary by Race/Ethnicity, Occupation, and Earnings* (2016) [hereinafter INST. FOR WOMEN'S POL'Y RESEARCH, *Briefing Paper*],https://iwpr.org/wp-content/uploads/wpallimport/files/iwpr-export/publications/B356.pdf.
[xvii] Amara Omeokwe, *Women Overtake Men as Majority of U.S. Workforce*, WALL ST. JOURNAL (Jan. 10, 2020), https://www.wsj.com/articles/women-overtake-men-as-majority-of-u-s-workforce-11578670615.
[xviii] ALEXANDRA CAWTHORNE & MELISSA ALPERT, CTR. FOR AM. PROGRESS, LABOR PAINS: IMPROVING EMPLOYMENT AND ECONOMIC SECURITY FOR PREGNANT WOMEN AND NEW MOTHERS 2 (2009), https://www.americanprogress.org/issues/women/report/2009/08/03/6599/labor-pains/

[Additional submission by Mr. Courtney follows:]

COURTNEY

January 27, 2020

The Honorable Joe Courtney
Member, House Committee on Education and Labor
2332 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Courtney,

I want to thank you for cosponsoring and supporting the Ensuring Lasting Smiles Act (H.R. 1379). This bill would require all private group and individual health insurance plans (including self-funded plans regulated by ERISA) to approve claims for medically-necessary treatments that restore bodily function to body parts that have been affected by congenital anomalies, commonly known as birth defects. In my case, those body parts include my mouth, teeth, and oral cavity due to Ectodermal Dysplasia.

My medical insurance denies all treatments for the mouth, teeth, and oral cavity, unless those parts are injured. But because my condition was congenital, my treatments get denied or delayed. This has resulted in me having a reduced ability to chew and nutritional deficiencies. Multiple times a day I have to drink prescription infant formula to get proper nutrients, which my medical insurance refuses to cover. I have been in speech therapy most of my life and have had 7 endoscopies since the age of 2, all because of my inability to chew and eat most foods.

The Ensuring Lasting Smiles Act would guarantee me not just a big smile but a new way of living a healthy, happy life physically, socially and psychologically. I hope that this bill advances and becomes law in 2020. Thanks again for your support.

Respectfully,

Caleb Andrew Locke

Caleb Andrew Locke (10-years old)
Connecticut and Rhode Island

[Additional submission by Ms. Jayapal follows:]

JAYAPAL

July 10, 2019

Dear Honorable Members of the United States Congress:

As organizations that represent people of color, we respectfully urge you to co-sponsor the "Medicare for All Act of 2019" (H.R. 1384/S. 1129).

Medicare for All, the only truly single-payer, universal health care system, guarantees that health care is a right and enables every person living in the United States to receive the health care they need to survive and thrive.

Despite many gains, 30 million people in the United States lack health insurance, and tens of millions of households have health insurance but cannot afford to receive the medical care they need. One in five working-age Americans report having problems paying their medical bills despite having health insurance, driven by pocketbook-busting premiums, copays and deductibles.[1]

Universal health care is also a racial justice necessity because communities of color, in particular, suffer from a lack of access to affordable health insurance.

People of color make up 42% of the nonelderly U.S. population, yet account for over half of the total nonelderly uninsured population. Latinx and Black people have significantly higher uninsured rates (19% and 11%, respectively) compared to white people.[2]

Medical debt remains a glaring issue for Black Americans. Nearly one in three Black Americans aged 18 to 64 has past-due medical bills.[3] Black uninsured populations face burdensome out-of-pocket medical expenses when seeking care, which often means they are forced to delay preventative care and get treated as a last resort – the most expensive form of treatment.[4]

Latinx patients are the most uninsured population in the United States today. Latinx individuals already comprise much of the workforce that is unable to get health coverage through their job. Lawmakers have curtailed the Affordable Care Act's health enrollment program, which has severely challenged the ability of outreach workers to reach Latinx patients for new coverage.

Undocumented Latinx patients suffer further as they are ineligible for government-funded insurance and subsidized private health plans. Despite the fact that undocumented adults pay taxes[5], they are ineligible to receive Medicaid health benefits and financial subsidies to buy health plans from the federal-state health insurance marketplaces.

Disturbingly, racial bias mars the entirety of American health care. In particular, Black maternal and prenatal health access remains in crisis levels. In the state of New York between 2013 and

2015, 54 Black women died for every 100,000 births -- nearly four times the rate of white women.[6]

Indeed, half of maternal deaths in our country are preventable.[7] While there are many reasons why Black mothers and mothers-to-be experience poor treatment and care, a lack of quality health access is a significant factor.

Medicaid – a lifeline for many people of color and low-income patients – is not accepted at many hospitals and doctors' offices. Black and low-income women are more likely than others to be treated at under-resourced hospitals, increasing the chances they may experience complications during and after childbirth. Hospital quality can account for nearly 50%t[8] of the racial disparity in maternal illness. With Medicare for All, there are no "out of network" provider limits. Patients can get the care they seek, when it is appropriate and convenient for them.

Communities of color need a health care system that rectifies these long-standing structural biases and challenges. Medicare for All is that system. Medicare for All universal health care would support the health and economic security of patients of color, including finally providing full health coverage for all reproductive health services, alongside controlling the costs of prescription drugs – both glaring affordability and access issues for low and moderate-income patients of color.

Some health plans sold on the federal and state health insurance marketplaces discriminate on the basis of drug affordability for certain diseases, such as HIV/AIDS. By categorizing medications for particular conditions in the highest co-payment "tier," these plans price out patients with those ailments. These additional co-payments can result in thousands of dollars a year in extra expenses, crushing millions of households of color as they seek the care they need to survive.

There is only one form of universal health care that covers everybody, without exception, and lowers overall health care expenditures. Just as the passage of Medicare over 50 years ago helped spur hospital integration and improved health access, it can today usher in true universal health care.

It is time for Medicare for All.[9] We implore you to join the movement in support of this bill.

Sincerely,

A. Philip Randolph Institute
Action Center on Race and the Economy (ACRE)
Black Women's Health Imperative
Center for Popular Democracy
Color of Change
League of United Latin American Citizens (LULAC)
NAACP
People's Action
Policy Link
United We Dream

[1] https://www.kff.org/health-costs/press-release/new-kaisernew-york-times-survey-finds-one-in-five-working-age-americans-with-health-insurance-report-problems-paying-medical-bills/
[2] https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/
[3] http://apps.urban.org/features/medical-debt-in-america/
[4] https://www.urban.org/urban-wire/past-due-medical-debt-problem-especially-black-americans
[5] https://www.vox.com/policy-and-politics/2017/4/17/15290950/undocumented-immigrants-file-tax-returns
[6]https://www.acog.org/-/media/Districts/District-II/Public/SMI/v2/SMIReview072017.pdf?dmc=1&ts=20180108T2349092055
[7]https://www.mhtf.org/2018/03/16/new-data-explore-why-preventable-maternal-deaths-continue-to-occur-in-the-united-states/
[8] http://www.ajog.org/article/S0002-9378(16)30202-2/pdf
[9] https://www.cnn.com/2015/07/28/opinions/das-gaffney-racial-injustice-health-care/index.html

[Additional submission by Mr. Johnson follows:]

MENU

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Home > Stories > Effort begins to reduce risk of death of S.D. mothers during childbirth

Effort begins to reduce risk of death of S.D. mothers during childbirth

By: Nick Lowrey | January 16, 2020

New or expectant mothers in South Dakota — and across the United States — are dying during or after childbirth at higher rates than in nearly every other industrialized nation, and evidence suggests as many as 60% of maternal deaths are preventable.

Nine mothers in South Dakota died in 2018 within a year of giving birth, and 10 South Dakota mothers died due to pregnancy complications within six weeks of giving birth from 2010 to 2015, according to federal data.

Experts say that in South Dakota, high rates of obesity, diabetes and smoking, as well as a trend toward giving birth at older ages, may all contribute to the relatively high maternal complication and death rate. A lack of access to

health care and inefficiencies or mistakes in the birthing process are also seen as factors. Native American women in South Dakota face a particularly high risk of death during pregnancy.

The state Department of Health has formed a new committee made up of medical professionals that will begin meeting later this year to address the risks during childbirth and seek solutions.

Giving birth is one of the most common reasons younger American women, including South Dakotans, are admitted to a hospital, with roughly 3.7 million births recorded nationally each year (about 12,000 in South Dakota annually.)

Between 2010 and 2015 in South Dakota, the Centers for Disease Control and Prevention estimates there were 10 "pregnancy-related" deaths, those that occurred during or within six weeks of a pregnancy ending and are directly due to a pregnancy complication. The number is an estimate based on birth and death records and is likely a conservative figure.

Maternal "pregnancy-associated" deaths — those that occur within a year of the end of a pregnancy but are not necessarily connected to the pregnancy — averaged 7.2 per year between 2010 and 2018, according to the state Department of Health. There were nine such deaths in 2018.

The CDC estimates that roughly 700 American women die due to pregnancy-related complications every year. In 2017, the U.S. maternal mortality rate was 19 deaths per 100,000 live births, according to the World Health Organization. Countries with similar economic conditions saw a much lower rate. The United Kingdom saw 7 deaths per 100,000 live births and Canada recorded 10 maternal deaths per 100,000 births that year.

About 50,000 women in the U.S. annually are estimated to experience life-threatening pregnancy complications such as heavy bleeding, organ failure or the dangerous blood-pressure condition called preeclampsia.

South Dakota does not keep data on the prevalence of severe pregnancy complications, but such problems are "not uncommon," according to Dr. Kimberlee McKay, who oversees obstetrics and gynecological services at Avera Health. The CDC estimates that severe pregnancy complications are up to 50 times more common than death.



Dr. Kimberlee McKay, Avera Health

Yet relatively little is known about how often complications arise. In South Dakota, there is no requirement for hospitals to publicly report how often they give new mothers blood transfusions or treat a pregnant woman for dangerously high blood pressure. Until this year, South Dakota didn't have a

statewide review process to study the factors causing pregnant women to die in childbirth.

Many experts believe a lack of systematic review of maternal deaths in each state has been a significant factor in why America has become, statistically, one of the most dangerous industrialized nations in which to give birth.

Data that does exist largely are based on national surveys of hospital admissions and discharge paperwork as well as analyses of death certificates and birth certificates. The data show that both maternal deaths and the incidents of life-threatening complications are significant and have been growing in the U.S. since at least 1987.

The occurrence of life-threatening complications, for example, rose by nearly 200% between 1993 and 2014, according to the CDC National Inpatient Sample, a random sample of the nation's hospital admissions. The data do not show whether the number of South Dakotans who experience severe pregnancy complications has risen.

The national rate of pregnancy-related deaths more than doubled between 1987, when the rate was 7.2 deaths per 100,000 births, and 2014, when the rate was 18 deaths per 100,000 births, according to the CDC Pregnancy Mortality Surveillance System, which surveys death certificates as a way to monitor pregnancy-related deaths.

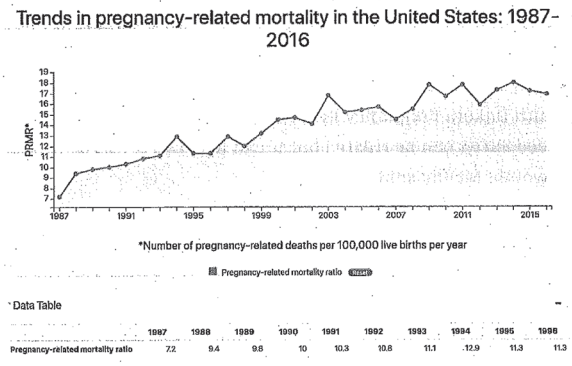
Existing data also show that roughly 60% of maternal deaths could be prevented. Researchers with the CDC have found that delivery hospitals could do a better job of creating standard procedures for monitoring and responding to emergencies such as high blood pressure and excessive bleeding in mothers before, during and after delivery.

South Dakota hospital systems are aware of the risks. At Avera Health, one of the state's largest hospital systems, McKay said she and her colleagues have been implementing new protocols for monitoring blood loss. At Sanford Health, another leading health provider in South Dakota, an innovative piece

of technology is helping hospital staff better monitor blood pressure in new mothers.

Renewed national focus on maternal health and safety has pushed South Dakota officials to take initial steps toward understanding and addressing the problem. Later this year, the state's new Maternal Mortality Review Committee will hold its first official meeting to analyze maternal deaths and try to figure out how to prevent more such deaths in the future.

"It may change what we think about maternal mortality," said Colleen Winter, division director for family and community health at the South Dakota Department of Health.



The Centers for Disease Control and Prevention have been tracking maternal mortality since 1987 through its Pregnancy Mortality Surveillance System, which compares death certificates to birth certificates to determine whether a death was pregnancy related or associated. The rate of maternal death has been increasing since 1987 and public health officials are beginning to grapple with the situation. The U.S. is one of only a handful of nations around the world to have seen a rising rate of maternal mortality over the last three decades. Source: Centers for Disease Control and Prevention

Causes of high maternal mortality varied

No single cause has been pegged as the reason for America's rising rates of maternal death and severe pregnancy complications. But the trend has

coincided with rising healthcare costs as well as rising rates of chronic conditions such as obesity and diabetes. The average age of women giving birth has risen, too. And, until this year, there really wasn't a standard for how hospitals were expected to identify, treat and train for responding to severe pregnancy complications.

"What's interesting about women in South Dakota is that we tend to be overweight and gain too much weight (during pregnancy). We have higher rates of smoking. We are rural, which people don't think of rurality as being a social determinant of health but in fact it is. And then we have the complications of obesity like diabetes, like hypertension, we have all of those things," McKay said.

The state has a particular problem with gestational diabetes, a condition that affects how the body processes sugar, McKay said. Roughly one in 10 South Dakotans who got pregnant in 2017 were diagnosed with the condition, according to the South Dakota Pregnancy Risk Assessment Survey. Gestational diabetes, if recognized early, can be treated but it can also cause a baby to grow larger in the womb, McKay said.

"If you have gestational diabetes, the downstream effects of that pregnancy are severe hypertension and big babies, and when you deliver a great big baby, a lot of times your uterus bleeds afterwards," McKay said.

One of South Dakota's biggest challenges when it comes to maternal health is proximity to health care. Most of the state is already considered a shortage area for primary healthcare. When it comes to maternal health, McKay described many of the state's rural areas as maternity deserts, meaning women must travel 30 minutes or more to see an OBGYN or to give birth in a hospital.

Access to quality care may be one of the biggest reasons that Native American women are almost twice as likely to die from pregnancy-related causes as white or Hispanic women, said Dr. Ashley Briggs, an OBGYN at Sanford Health.

She has been working with the federal Indian Health Service and other critical access hospitals in the Dakotas to provide better prenatal and post-pregnancy care in rural areas. In 2018, Briggs helped create a multi-state group of healthcare providers and public health officials who seek to improve both maternal and infant health in both states.

"We are trying to do things that focus on the specific concerns of Native Americans," Briggs said.



Dr. Ashley Briggs, Sanford Health

Hospitals also share some of the blame for the country's rising maternal death rate. Experts say that not enough attention has been paid to using

standardized research-based best practices to both watch for and treat complications, such as heavy bleeding or high blood pressure in pregnant women before the situation gets out of hand.

The Alliance for Innovation on Maternal Health within the Council on Patient Safety in Women's Healthcare has spent years trying to get hospitals to adopt sets of standardized procedures and practices, called bundles, that can be taught to anyone who works in a birthing hospital.

Many of the bundles are based on practices originally developed in California by the California Maternal Quality Care Collaborative. Implementation of the bundles helped reduce that state's maternal mortality rate by 55% between 2006 and 2013. California's maternal death rate during those years fell from 16.9 deaths per 100,000 births to 7.3 per 100,000. California now has one of the lowest maternal mortality rates in the U.S, according to the state's maternal mortality review committee.

The bundles include such practices as weighing blood absorbing pads in order to more accurately measure blood loss during delivery and making sure every delivery room has easily accessed kits for treating heavy bleeding. Hospitals also develop standard practices for monitoring blood pressure, including how and when to respond if a pregnant woman's blood pressure gets too high. The new standards also include annual training requirements for hospital staff.

Avera Health has been implementing procedures that conform to the AIM bundles for both high blood pressure and bleeding for a few years now, McKay said. One of the hospital system's most recently added practices is weighing blood absorbing pads to get a more accurate measure of a mother's blood loss during and after birth.

"I think our teams have done just a tremendous job of interrupting the bad things that can happen in deliveries because of the approach we've taken," McKay said.

Most hospitals that deliver babies in the U.S. will be forced to have such policies in place by July 1, 2020. The Joint Commission is a nonprofit group that evaluates performance for about 80% of U.S. hospitals, including most hospitals in South Dakota. The group recently updated its accreditation requirements for labor and delivery hospitals to create procedures and training regimes that conform to AIM supported maternal care bundles for monitoring and responding to high blood pressure and bleeding.

Sanford Health also has been developing its own set of practices in response to the Joint Commission's new requirements to improve patient safety, Briggs said. One innovation the hospital system plans to take advantage of is a way to automatically alert doctors and nurses when a patient's blood pressure is recorded as dangerously high in their electronic medical record. The technology will help prevent a high blood pressure reading from being missed and going untreated.

"We are all human and we all make mistakes. I think these standards are a way to head that off," Briggs said.

Having new protocols in place won't solve all of the problems, McKay said. Medical errors, whether they involve pregnant women or not, tend to be caused by a failure to recognize when a problem occurs or a failure to communicate about the problem, she said. While putting the protocols in place is a good first step, hospitals will need to adopt a more team-based culture to implement them.

"You can put a protocol in place all day long, but unless you address the culture and really adopt a culture of safety, you're not going to be successful at implementation," McKay said.

Despite ongoing efforts to prevent maternal deaths at the state's hospitals, physicians and public health officials say they need to get a better understanding of maternal mortality in South Dakota.

"We don't have complete data," said Winter, of the Department of Health.

"They were very interested in improving outcomes for moms and getting a better handle on the data for our state ... any maternal death is too many. Our numbers are smaller, but we'd rather have none." -- Colleen Winter, division director for family and community health at the South Dakota Department of Health

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Committee formed to improve safety

At the end of 2018, South Dakota was one of only nine states that had not established a Maternal Mortality Review Committee to analyze each death of a pregnant or recently pregnant woman. Establishing a state MMRC is regarded by the CDC and the Association of Maternal and Child Health Programs as a necessary first step toward lowering the rate of maternal deaths.

"They were very interested in improving outcomes for moms and getting a better handle on the data for our state," Winter said.

After months of laying the groundwork, Winter said South Dakota's MMRC will hold its first meeting later this year to evaluate all nine maternity-associated deaths reported in 2018. The evaluations will help public health officials and healthcare providers pinpoint which areas of maternal health need more focus. The state has had success with a similar review committee that helped reduce the state's rate of infant deaths.

"In the case of infant mortality we found that infants were dying as a result of not having safe sleep environments and so we implemented a statewide safe sleep program," Winter said. "I feel like we'll learn a lot from maternal mortality review."

Because the DOH created the new MMRC without any additional funding from taxpayers, its members will be volunteers from the South Dakota medical community, Winter said. The state's hospitals also will be asked to provide access to medical records for each maternal death recorded in the state.

That access will be provided through a memorandum of understanding between the DOH and each hospital or hospital system. A DOH employee who has been assigned to work on maternal health will collect the pertinent information from each set of medical records and format a report on each death for the committee to review.

The committee may take years to devise policy recommendations. Maternal deaths are rare, of the roughly 11,890 women who gave birth in South Dakota in 2018, only nine died. Such a small number of deaths can make it difficult to draw conclusions, Winter said. But, she said, the MMRC will make a difference.

"Any maternal death is too many," Winter said. "Our numbers are smaller ... but we'd rather have none."

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ABOUT NICK LOWREY

[Additional submission by Mr. Morelle follows:]

Johnson & Johnson

Worldwide Government Affairs & Policy

January 28, 2020

The Honorable Frederica Wilson
2445 Rayburn House Office Building
Washington, DC 20515

The Honorable Tim Walberg
2266 Rayburn House Office Building
Washington, DC 20515

Dear Chairwoman Wilson and Ranking Member Walberg:

I am writing to you on behalf of Johnson & Johnson and our 140,000 global employees to thank the Education and Labor Committee for holding today's hearing "Expecting More: Addressing America's Maternal and Infant Health Crisis." We applaud your leadership and efforts to address this urgent health crisis affecting families across the country.

Maternal mortality and morbidity have become a crisis in the United States. The U.S. is the only advanced economy, and one of only eight nations globally, to see an increase in maternal deaths in recent years. While women of all races and cultures in the U.S. are at risk for pregnancy-related complications, maternal death rates are disproportionately higher for women of color, low-income women, and women living in rural areas.

Johnson & Johnson is committed to the goal of eliminating preventable maternal deaths globally, and believes congressional action is a crucial part of the solution. We are encouraged by the bipartisan engagement to address this crisis. We urge you to consider the following to include in any bipartisan legislative effort:

- **Full implementation of** Maternal Mortality Review Committees (MMRCs) to study data on the underlying causes of maternal death and identify strategies to help combat it, and accessibility of MMRC data across states to support shared learning and best practice development;
- **Access** to comprehensive prenatal and postnatal care through Medicaid and other payers;
- **Medicaid** coverage and expansion that offers important **maternal health benefits,** including a full year of continuous Medicaid coverage for beneficiaries;
- More healthcare provider **education on implicit bias, racial disparities** and the skills to provide culturally appropriate approaches to addressing maternal deaths and morbidity;
- Robust **payer and provider guidelines** to reduce or prevent maternal mortality and morbidity;
- **Increased access in rural areas** to healthcare facilities, providers and transportation services;
- Implementation of **prevention-focused value-based maternity care programs** that seek to measure impact, and improve outcomes and arrive at population-level payment models;
- **Addressing social determinants of health** (SDH) through innovative care models; and
- **Enactment of workforce policies**, including those relating to reimbursement for and access to a full range of maternal healthcare providers that seek to reduce maternal morbidity and mortality, as well as paid family leave.

We believe that good health is the foundation of vibrant lives, thriving communities and societal progress. For more than 130 years, Johnson & Johnson continues to keep people well at every age and every stage of life. By working together, we will reduce the number of maternal deaths in the U.S. Thank you for your continued leadership and attention to this urgent public health crisis.

Sincerely,

Jane M. Adams
Vice President, Federal Affairs

Cc: The Honorable Bobby Scott, Chairman, Education & Labor Committee
The Honorable Virginia Scott, Ranking Member, Education & Labor Committee

1350 I Street NW, Suite 1210, Washington, DC 20005 + 202-589-1000 www.jnj.com

[Additional submissions by Mr. Scott follow:]

NACCHO
National Association of County & City Health Officials
The National Connection for Local Public Health

January 27, 2020

The Honorable Alma Adams
Chairwoman
Education and Labor
Workforce Protections Subcommittee
2176 Rayburn House Office Building
Washington, DC 20515

The Honorable Bradley Byrne
Ranking Member
Education and Labor
Workforce Protections Subcommittee
2101 Rayburn House Office Building
Washington, DC 20515

Dear Chairwoman Adams and Representative Byrne:

I write to thank you for holding the hearing: "Expecting More: Addressing America's Maternal and Infant Health Crisis." The National Association of County and City Health Officials (NACCHO) represents the nation's nearly 3,000 local health departments across the country, who are responsible for safeguarding the health of all Americans. These city, county, metropolitan, district, and tribal departments are on the front lines of protecting maternal and child health in communities across the nation.

Local health departments are key partners with Congress and state and local governments to protect maternal and infant health. According to NACCHO's most recent National Profile of Local Health Departments, about one-third of local health departments directly provide prenatal and well-baby care. In addition, 88% of local health departments provide childhood immunizations to protect children from preventable infectious diseases including measles, influenza, and pertussis (whooping cough.) Two-thirds of local health departments also operate the local Women, Infant, and Child (WIC) program, and 60% engage in home visiting programs. In many areas local health departments are a consistent, and sometimes the only, sources of support for low-income and minority women at the highest risk for maternal mortality and morbidity.[1]

Local health departments have also been leaders in addressing maternal and infant mortality in their communities. For example, the Baltimore City Health Department in Maryland has augmented the state of Maryland's Maternal Mortality Review Process with a Baltimore-focused severe maternal morbidity review process. For every maternal death, there are significantly more near misses that greatly impact the lives and health of mothers and their babies. The city health department's relationships with local hospitals allow for facility-based reviews, citywide aggregation of data, and selected maternal interviews designed to transform how obstetric care is provided. The Champaign-Urbana Public Health District in Illinois aims to improve maternal health through early identification of risk factors during pregnancy and the postpartum period. They currently conduct research examining racial differences in perinatal depression and explore how depressive symptoms and other risk factors contribute to adverse birth outcomes. Alameda County in California held "Club Mom" baby showers in neighborhoods with the

[1] Additional information can be found in NACCHO's National Profile of Local Health Departments, 2016, available here: http://nacchoprofilestudy.org/wp-content/uploads/2017/01/Figure7-5.jpg.

1201 Eye Street NW, Fourth Floor, Washington, DC 20005 P (202) 783 5550 F (202) 783 1583 www.naccho.org

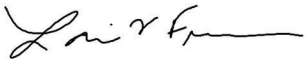
Public Health
Prevent. Promote. Protect.

highest levels of adverse birth outcomes and raffled off baby supplies while connecting women to the county's prenatal services.

Moreover, local health departments have been on the front lines in reducing infant mortality. Many lead or participate in fetal and infant mortality reviews, interdisciplinary panels that investigate fetal and infant deaths to identify gaps in systems and services and encourage preventive measures. As deaths from congenital syphilis continue to rise, for example, local health departments collaborate with public and private providers to support screening and treatment for pregnant people and infants.

NACCHO looks forward to continuing to work with Congress to address the challenges to the health and well-being of women and children. Please contact Eli Briggs, NACCHO Senior Director of Government Affairs at ebriggs@naccho.org with any questions.

Sincerely,



Lori Tremmel Freeman, MBA
Chief Executive Officer

Jan. 27, 2020

The Honorable Frederica S. Wilson
Chair, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tim Walberg
Ranking Member, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairwoman Wilson and Ranking Member Walberg:

The undersigned organizations write to express our support for HR 1379, the Ensuring Lasting Smiles Act (ELSA). We appreciate your leadership in recognizing the importance of this bill by including it as part of the Health, Employment, Labor, and Pensions Subcommittee's Jan. 28 "Expecting More: Addressing America's Maternal and Infant Health Crisis" hearing.

This legislation – with more than 260 bipartisan cosponsors – will have a direct impact on patients and will eliminate the existing burdens that prevent access to necessary diagnosis and treatment for those with congenital craniofacial anomalies, such as cleft lip and palate, skeletal and maxillofacial abnormalities, facial paralysis, microtia, hypodontia, and craniosynostosis. Specifically, if enacted, ELSA will ensure all group and individual health plans cover medically necessary services, including needed dental procedures such as orthodontic or prosthodontic support, as a result of a congenital anomaly. It would exclude coverage for cosmetic procedures or surgery on normal structures.

The Centers for Disease Control and Prevention (CDC) classifies birth defects as "common, costly, and critical" and reports that one in 33 newborns in the United States suffers from a congenital anomaly. Craniofacial anomalies, for example, can restrict a patient's ability to breathe, eat, and speak in a normal manner. Therefore, highly personalized surgery to repair an anomaly helps the patient grow and function normally. Early intervention by a team of specialists, including plastic surgeons, oral and maxillofacial surgeons, pediatric dentists, orthodontists, dermatologists and speech therapists, is necessary to assess and oversee the patient's treatment and development, sometimes over the course of several years.

Most private health plans provide coverage for the surgical treatment of congenital anomalies and many states require insurers to provide coverage of any health services related to congenital anomalies or birth defects. Despite this, health plans often deny claims and appeals for oral or dental-related procedures – like orthodontia and dental implants – or other procedures, which are often crucial to the overall success of treatment, claiming these services are cosmetic.

Severe dental anomalies are a common symptom of many craniofacial anomaly conditions requiring serious medical treatment that is outside the scope of procedures covered by dental plans. As a result, patients are forced to incur significant out-of-pocket costs on medically necessary reconstructive dental care related to their disorder during their lifetime. When private insurance denies a child's reconstructive surgery, families many times end up turning to Medicaid, SCHIP, or other state-sponsored programs for coverage.

The Ensuring Lasting Smiles Act would address these coverage denials and ensure that all patients with birth defects or anomalies get the treatment they need.

For these reasons, we support the Ensuring Lasting Smiles Act and urge members of your subcommittee to help advance this bill through the House.

Sincerely,

Academy of General Dentistry

American Academy of Dermatology Association

American Academy of Neurology

American Academy of Pediatric Dentistry

American Academy of Oral and Maxillofacial Pathology

American Academy of Oral and Maxillofacial Radiology

American Association of Oral and Maxillofacial Surgeons

American Association of Orthodontists

American Association of Women Dentists

American Behcet's Disease Association

American College of Surgeons

American Dental Association

American Society for Dermatologic Surgery Association

American Society of Dentist Anesthesiologists

American Society of Plastic Surgeons

FACES: The National Craniofacial Association

International Pemphigus and Pemphigoid Foundation

March of Dimes

M-CM Network

National Foundation for Ectodermal Dysplasias

National Organization for Rare Disorders

Operation Smile

Pathways for Rare and Orphan Studies

Written Statement Submitted by Mrs. Becky M. Abbott, MPH, Patient Advocate, On Behalf of the National Foundation for Ectodermal Dysplasias, Supporting the Ensuring Lasting Smiles Act (H.R.1379)

Hello, Health, Employment, Labor, and Pensions Subcommittee Chairwoman Wilson, Ranking Member Walberg, and Workforce Protections Subcommittee Chairwoman Adams, and Ranking Member Byrne, and distinguished Members of this Committee. I am honored to be given the opportunity to submit my written statement to this committee. My name is Becky M. Abbott, and I am a passionate patient advocate and co-chair of the National Foundation for Ectodermal Dysplasias Family-Driven Advocacy Committee. I live in South-Eastern Wisconsin, with my husband of 20 years, Tom, and our sons, Aidan, age 15, affected my X-linked Hypohidrotic Ectodermal Dysplasias (XLHED), and Ryder, age 7.

I am submitting this statement to ask for your support in advancing **H.R.1379, the Ensuring Lasting Smiles Act**, on behalf of the estimated 4% of Americans, like my son Aidan, who are diagnosed with a congenital anomaly, more commonly known as a birth defect. As of Monday, January 27th, 2020, the House bill, H.R.1379, had 274 bipartisan cosponsors (194 Democrats and 80 Republicans), including 15 members of the H.E.L.P. Subcommittee and 35 members overall from the Education & Labor Committee. The identical companion Senate bill, S.560, had 37 bipartisan cosponsors (19 Republicans and 18 Democrats).

The Ensuring Lasting Smiles Act:

This bipartisan, bicameral bill will ensure that all private group and individual health plans (including self-funded plans regulated by ERISA) provide coverages for Americans who are born with congenital anomalies and then require medically-necessary treatments to restore function to missing, poorly functioning, or non-functioning body parts that resulted directly from the diagnosed anomaly. It further clarifies the inclusion of adjunctive dental, orthodontic, and prosthodontic services for congenital anomalies that impact the mouth, teeth, and oral cavity.

The intent of this bill might seem like commonsense. It is. Health insurance should approve claims for medically-necessary treatments of congenital anomalies. In many cases, that is happening, especially when you think of more well-known anomalies like congenital heart defects, missing or defective limbs, or neural tube defects like Spina Bifida.

However, the problem is that health insurance companies systematically deny or delay medically-necessary treatments for Americans diagnosed with a host of other congenital anomalies, such as those that affect the teeth, mouth, and oral cavity, like Ectodermal Dysplasia. Insurers deny treatments for these congenital anomalies by calling the treatments “cosmetic” and “not medically-necessary,” despite an official medical diagnosis and physician-approved care plan. Or insurers state that the requested procedures are “not covered benefits” because they appear to be dental-related, even though they are directly linked to an underlying medical

condition.

The Reason for our Advocacy:

My son Aidan was born on January 17, 2005 with health issues and was kept in the hospital for four days. Since birth, he has had chronic health issues and was seen by medical professionals and specialists often. At around the age of 2-3 years old, we noticed that Aidan was missing several of his teeth and we took him to our family dentist for an evaluation. The family dentist referred us to Children's Hospital of Wisconsin due to the complexity of Aidan's congenital anomaly. During our first appointment with a pediatric dentist at Children's Dental Center, the dentist mentioned that she believed Aidan had a rare disorder called Ectodermal Dysplasias, due to his missing teeth and health issues, and recommended that he be seen by a geneticist.

Our family made an appointment with the geneticist, and they confirmed the dentist's diagnosis of Ectodermal Dysplasia. Both the pediatric dentist and geneticist noted that Aidan's treatments and procedures to repair his congenital anomaly and replace his missing teeth would be covered under our medical-health insurance. The dentist at Children's recommended that Aidan's treatment begin with a lower prosthetic to help with chewing and his speech. That prosthetic was denied on the basis that it served a "cosmetic" purpose. After going through the denial and appeals process, our insurance approved Aidan's first prosthetic and related dental work.

However, in the meantime, Aidan developed severe speech, swallowing, and choking issues. Aidan was unable to communicate with family, classmates, or teachers and was referred to a speech therapist and subsequent speech therapy that lasted nearly 3.5 years. He also developed swallowing and choking issues and was referred to specialists at Children's, where he underwent a swallowing study, and endoscopy to determine that his missing teeth was causing him to have issues swallowing. Our family practitioner also prescribed Prilosec, as he believed Aidan had GERD. The endoscopy determined that Aidan did not have GERD and the medication was discontinued. All of his health issues were related to his missing teeth. His diet was altered, and he no longer wanted to eat whole foods for fear that he would choke on his food, as he had done several times in the past. We started supplementing his meals with food pouches and Pediasure to ensure that he was receiving the nutrients he needed. As Aidan refused to eat many of the solid foods that he was recommended at that age, he also developed chronic constipation and severe stomach pain. He was referred to a gastroenterologist who prescribed constipation medication to help relieve his symptoms. These developing issues lasted for several years.

Once his lower denture was placed, he began to develop better speech, and he was able to chew better. He was still hesitant to eat solid foods for quite some time, and it took several years for him to be able to chew slowly enough and feel confident that his food would be digested properly without choking. We believe that most of these issues could have been avoided if the prosthetic was approved in a timely manner.

Over the next several years, Aidan went back to his dental specialist for frequent checkups to determine what the next steps of treatment would involve. At one of his follow-up appointments, the dentist mentioned that, due to Aidan's missing teeth, his two front teeth had erupted too far and were too long. They also noted that the same teeth were at risk for trauma. They recommended that Aidan have orthodontia to move teeth into place to protect those front teeth from risk of trauma. The coverage for that treatment was denied.

On a follow up appointment, his dental specialists believe he should have a frenectomy to remove the tissue that had grown in between the two front teeth, as well as four teeth removed to make way for other teeth to be moved into place to protect his two front teeth. The frenectomy was approved, but the subsequent removal of the four teeth was repeatedly denied. The insurance company gave different reasons at different stages of the appeals/denials process and ultimately denied the treatment, saying that the treatment was needed for his upcoming orthodontia, even though the service did not include the use of orthodontia.

Since Aidan's initial prosthetic, we have had to fight insurance for most of his complex treatments. His case has gone to a third-party medical review board. The review board determined that his treatments are medically necessary and that the suggested treatment plan is suitable for the repair of Aidan's congenital anomaly. Even so, our insurance provider used every loophole available to continue to deny his services.

One of his initial treatment plans was quoted at approximately $3,080. Since Aidan did not receive that treatment in a timely manner, his treatment plan was forced to change, and the cost of the new treatment has increased to $6,180. Each time his treatment is delayed, he develops new issues and requires additional treatment. His jaw needs to be leveled and aligned, and he has had numerous follow-up appointments, almost weekly, to make adjustments and changes to his dentition.

This is just the start of Aidan's complex treatments, and these treatments will continue for the rest of his life. As Aidan's jaw continues to grow, he will most likely need bone grafting and implants. Our medical insurance policy includes a congenital anomalies clause that includes coverage for the repair of congenital anomalies. The state of Wisconsin also has a state statute that covers the repair of all congenital anomalies from the time of birth. However, our insurance plan is self-funded and federally regulated. Therefore, our plan does not need to adhere to state statutes. Our health insurance company has repeatedly asked for supporting documentation, but no matter how much information we provide from his team of physicians, all of which indicates that his treatments are medically-necessary and required to repair his congenital anomaly, they are still denied.

What is Ectodermal Dysplasias?

Ectodermal Dysplasia is a congenital anomaly that affects the development of the hair, skin, sweat and saliva glands, teeth, and sometimes other body parts, depending on the specific diagnosis. There are at least 180 known variants of Ectodermal Dysplasia—some are more severe and impact limb development, eyesight, or in some cases even lead to death due to infections caused by severe skin erosions. These traits result in a lifetime of medical needs across multiple medical disciplines.

But it is specifically the issues with the teeth, oral cavity, and bone structures supporting the teeth that has galvanized our families to lead the charge in advocating for the Ensuring Lasting Smiles Act. Teeth may be missing or completely absent; their eruption is significantly delayed; the enamel is weak, making the teeth brittle; they will often be conical in shape instead of squared; and the lack of teeth causes the jawbone and gum line to recede and decay.

What Are the Physical and Financial Impacts of Claims Denials and Delays on Families?

The patient's health suffers when insurers deny or delay claims for medically-necessary treatments that are meant to restore bodily function as a result of a congenital anomaly. These treatments are not optional. Beyond the physical impact of these denials and delays, the financial burden of paying for this medically-necessary care 100% out-of-pocket is substantial and varies depending on the unique medical care plan that is tailored to fit the individual patient's medical needs. The National Foundation for Ectodermal Dysplasias estimates that some individuals will pay upwards of $150,000 out-of-pocket in their lifetime just for medically-necessary treatments related to the mouth, teeth, and oral cavity.

Coverages for congenital anomalies already exist in an overwhelming majority of private health plans, but insurance companies bypass those clauses by using the aforementioned "cosmetic" loophole or inappropriately applied "dental exclusion." As a result, our families must make tough and often life-altering financial trade-offs by trying to save money for teeth instead of college or retirement, or taking out second mortgages, to pay for these medically-necessary treatments, even though we are already paying for congenital anomaly coverages through our health plan's premiums. So why are health insurers bypassing congenital anomaly clauses within their own policies? Why are health plans separating the mouth and teeth from the rest of the body when directly related to an underlying congenital anomaly?

Moreover, the need for (and costs associated with) secondary treatments—which result directly from the initial denials and delays—would drastically be reduced or even eliminated if health plans appropriately approved claims for medically-necessary treatments such as dentures, reconstructive surgeries, and dental implants. Often, the cumulative cost of these secondary treatments far exceeds the cost of the initial medically-necessary treatment. For example,

approving the initial medically-necessary claim for prosthetic teeth would very likely result in an improved ability to chew (reducing or eliminating the need for ENT and GI specialists to conduct swallow studies or endoscopies), improved nutrition (reducing or eliminating the need for appointments with nutritionists who prescribe nutritional supplements, medications, or meal-replacement products), improved speech (reducing the need for speech evaluations and therapy), and improved self-esteem and mental health (reducing the need for psychotherapy appointments with mental health professionals). Approving the claims for medically-necessary treatments would not only improve the health of the patient, but also reduce costs to the patient and insurance company.

When medically necessary treatments that are recommended by the treating physician are not administered in a timely manner, severe secondary issues can develop. These secondary issues can often be life-threatening and chronically affect day to day life.

Starting at a very young age, Aidan was unable to chew his food properly and often choked while he was eating. We initially started cutting his food in very small portions to aid in his digestion, however his choking issues continued. After many months of concern, we made the decision to take him to specialists who would administer swallowing studies and an endoscopy to ensure that there wasn't an underlying issue. The lack of variety of foods also led to developing gastrointestinal issues and severe stomach pain. A gastrointestinal specialist prescribed a medication that would help Aidan and reduce his chronic constipation and stomach pain.

Please take a moment and imagine living as Aidan has with this congenital anomaly:

1. Classmates, teachers, and family members are unable to understand what you are saying and you often play alone at a young age because you cannot communicate with classmates or ask them to participate in activities.
2. You have to forgo class snacks and birthday treats, because you are afraid that you will choke on those foods, especially fruit snacks that are harder to chew.
3. Kids and classmates ask what is wrong with you and your teeth.
4. Each day you become frustrated that you cannot explain what you need or are asking for. You resort to grabbing your teachers, parents, or grandparents hand and escorting them to the refrigerator, bathroom, or whatever you need and then try and explain what you need without being able to form words correctly.
5. You live with chronic stomach aches and end up spending hours of your day in the bathroom, hoping to find some relief.
6. You are forced to take numerous days off from school and miss class, to go to repeated doctor appointments, procedures, and evaluations for unneeded medical issues that could have been avoided.
7. For many years, you are taken out of class several days a week to meet with a speech

therapist to learn how to use your tongue properly to pronounce the correct sound patterns.
8. You keep your food in your mouth and wait for it to soften enough so it's easier to chew.
9. You take every last minute of lunch time to ensure that you have chewed your food enough so you won't choke because of anxiety from past episodes where you have choked on food.

If there was a way to ensure that most of these issues could be reduced or eliminated, wouldn't you do everything to the best of your ability to make sure they didn't happen? That is the very reason why this bill is necessary--to put an end to the unnecessary and needless struggles.

What is the Foundation for this Bill?

The foundation of this federal bill rests on two key points. First, all 50 U.S. states have congenital anomaly statutes, and these are usually written in open-ended ways as if all medically-necessary treatments for all medically-diagnosed congenital anomalies are supposed to be covered health benefits. These state laws apply to all private group and individual health plans issued in that state, otherwise known as "fully-insured" health plans. ("Self-funded" health plans, which are regulated at the federal level, do not have to abide by state laws.) Second, and as previously stated, an overwhelming majority of private health plans—both "fully insured" and "self-funded" plans—include benefits for medically-necessary treatments of congenital anomalies.

Even so, health plans continue to use loopholes and inappropriately applied dental exclusions to bypass the state laws and congenital anomaly clauses that exist in most health plans.

My husband has worked for the Washington County Sheriff's office for thirty years as a law enforcement officer. He has paid deductibles and premiums for the length of his career. When Aidan's treatments were being denied, we brought the Wisconsin State Congenital Anomalies Statute to their attention. Our original thought was that his employer needed to be educated on Aidan's congenital anomaly and that they were unaware of the coverage mandate in the state statute. My husband's employer maintains a "self-funded," high-deductible medical plan. Due to the plans "self-funded" status, we were informed that his employer did not have to abide by state statutes as the plan is federally regulated. Therefore the state statutes do not protect families like ours that have children born with complex congenital anomalies.

Approximately 110 million Americans have medical insurance coverage through a "self-funded" plan. With the growing popularity of these plans, and an increasing number of employers migrating to these plans, this leaves families like mine to navigate through the convoluted appeals and denials process with little to no recourse.

Closing:

In closing, I want to thank you for taking the time to read my statement in support of the Ensuring Lasting Smiles Act. Families in our community have struggled far too long, and we need your help to put an end to this issue. Our families have endured years of stress, heartbreak and financial distress, while insurance companies recklessly delay and deny medically necessary treatments for our kids and family members. We are asking that all medically-necessary repairs of congenital anomalies be treated equally, regardless of the location on the body. Our children and family members should not be treated differently and denied coverage based on loopholes that insurance providers are all too eager to use.

We must close the loopholes and unintended coverage gaps that health insurers use to bypass state congenital anomaly laws and their contractual obligations to approve claims for medically-necessary treatments of congenital anomalies. That is exactly what H.R.1379, the Ensuring Lasting Smiles Act, will do.

Thank you to our allies in this fight; Congressman Peterson, Congressman Riggleman, Senator Baldwin, and Senator Ernst for introducing this bill. And thank you to our co-sponsors in the U.S. House of Representatives and U.S. Senate for listening to our stories and showing your support. On behalf of the individuals and families who are born with congenital anomalies, I ask that you do everything in your power to advance this bill to ensure that all individuals like my son Aidan, get the treatments they need to live long, healthy and productive lives.

Attachment:

1. Ectodermal Dysplasia Patient Stories

2. List of Organizations Currently Supporting the “Ensuring Lasting Smiles Act”

Attachment 1. Ectodermal Dysplasia Patient Stories

These stories are representative of the Ectodermal Dysplasias community that has faced significant health setbacks when trying to get medically-necessary treatments to restore function to the mouth and teeth due to a congenital anomaly.

Kevin Koser, on behalf of his son, Kannon Koser (4-years old), of Virginia.
Kannon was born in September 2015. It was—and still is—one of the happiest days of my wife's and my life. There were no signs that anything was wrong. But it is important to understand that not all congenital anomalies present their symptoms immediately at birth. At a routine dermatology appointment when Kannon was 9-months old, the doctor recognized some of the clinical traits of Ectodermal Dysplasia in our son Kannon: his hair was sparse and platinum white; his skin was prone to rashes; he did not sweat; and there were no signs of teeth. Genetic testing was conducted when Kannon was 1-year old, which confirmed the diagnosis.

Kannon is now 4-years old and just recently sprouted his first tooth. X-rays indicate that he only has four (4) total teeth. A child without Ectodermal Dysplasia typically grows 20 teeth, and an adult grows between 28-32 teeth.

Please put yourself in Kannon's shoes. Imagine the drastic impact this would have on your health and quality of life:

- Your diet is severely restricted—Kannon's diet is limited to soft foods like sliced fruits, hummus with dissolvable crackers, PB&J sandwiches, and pancakes. He is physically unable to eat nutritious foods like fruits or vegetables that are crunchy, and he is unable to eat protein-rich foods like meats or nuts that require teeth to chew.
- Your limited diet results in a lack of proper nutrition, which is the foundation for cognitive and physical development, so you'll likely need daily supplements or meal-replacement products.
- Even with a diet of soft or pureed foods, you'll be prone to choking because you can't chew and have reduced saliva, which is a catalyst for proper digestion.
- Your inability to chew results in gastrointestinal (GI) issues, such as constipation, irritable bowel syndrome; cramping; or ulcers. Otolaryngologists (or ENT) and GI specialists will conduct swallowing studies, and you'll be put under general anesthesia so they can examine your stomach and digestive tract with a scope.
- You struggle to speak properly, requiring speech evaluations and years of speech therapy.
- As your jawbone and gum line decay and recede from the lack of teeth, you require multiple, complex bone grafting surgeries to reconstruct your jaw and facial structures.
- The list of secondary medical issues goes on. You'll need a team of physicians and specialists across multiple disciplines, all of whom tell you that your health is suffering because you don't have a mouth full of functioning teeth.

While there is no cure, and while everyone's medical care plan varies due to differences in how the traits present themselves in the patient, there are several common treatments that are medically-necessary to manage these issues. These treatments are not optional; they must be conducted to restore function to the mouth and for the patient to live a healthy life.

- First, prosthetic teeth (or dentures) starting between the ages of 2-5 and replaced every 1-3 years as the mouth grows.
- Second, surgeries to reconstruct and replace the decaying jawbone and gum line through grafting. The bone is necessary for dentures to rest upon and for our 3rd common treatment, dental implants, to be installed.
- Permanent dental implants are typically installed once an individual's mouth stops growing, usually around age 20. These also help prevent further bone decay through oseointegration.

Last Christmas, Kannon asked Santa Claus for teeth so he could "chomp big bites" of food like other kids in his class. Think about that. Our then 3-year old little boy—who loves dinosaurs, dragons, and superheroes—asked for teeth for Christmas. We began pursuing dentures for him, in accordance with a treatment plan established by oral and maxillofacial specialists. Imagine our heartbreak when our health plan told us that "any services relating to his teeth or intra-oral structures supporting the teeth are not a covered benefit," even though the same policy has mandated coverages for medically-necessary treatments of congenital anomalies. This will force us to pay for his medically-necessary treatments 100% out-of-pocket.

Jennifer Steele, on behalf of her daughter, Allison Steele (13-years old), and son, Bennett Steele (4-years old), of Iowa. Living with Ectodermal Dysplasia is part of our everyday life. We have two children, Alli (13) and Bennett (4), who are affected. Alli was diagnosed at age 6, and Bennett was diagnosed at age 4. Two of the largest concerns are their inability to sweat and their missing teeth. We have found ways to adapt and control overheating through various cooling products and methods. Their health and smiles mean everything to us, as we want nothing more than our kids to be healthy and happy. We live everyday with Ectodermal Dysplasia, yet it doesn't stop us from enjoying and loving each day.

Missing teeth makes it very challenging to chew food, and a lack of saliva production makes it easier to choke on food. Nutrition is a major concern and reality that we live with daily. Proper nutrition is directly linked to overall health and growth in children. Lack of teeth also causes the jawbone to deteriorate. As a result of missing teeth, Alli has had several procedures, including swallow studies, an upper endoscopy (or EGD), along with frequent medical appointments and tests by several specialists in an attempt to diagnosis and treat her severe GI symptoms that kept her on the verge of failure to thrive for several years due to her abnormal oral development. These tests and medical appointments could have been avoided with proper treatments, by improving her ability to initiate the digestion process in her mouth, like you experience each

time something enters your mouth. She only has one molar, which results in an inability to properly mash or chew food. She is limited on what she can eat, and the foods that are the most difficult are the healthy foods, like vegetables and meat. In the next 9-12 months, she will be ready to be fitted for her first partial denture. Who at the age of 13 wants to wear a denture? Alli does. She wants to have enough teeth in her mouth that she can easily chew her food for the first time in her life. Missing teeth also has had a negative impact on her mental health and self-esteem. She wants to be confident with her smile. This medically necessary process will be a 100% out of pocket cost, even though this is a result of a birth defect.

Alli received her first set of braces at age 7, due to her teeth twisting, turning, and moving into the space that is available in her mouth due to missing teeth. We traveled 260 miles round-trip to the University of Iowa every 3-6 weeks for 4-5 months because there wasn't a local orthodontist that was comfortable with treating her. In December 2016, Alli began the process for her second set of braces, this time requiring only 52 miles round-trip from home to Ankeny, Iowa. Due to the complexity of her dental condition, we make the trip to the orthodontist every 3-4 weeks. She will likely require one more set of braces before she moves on to the more permanent solutions of bone grafting for her jaw and dental implants, which will begin between ages 18-21. Alli currently sees a family dentist in West Des Moines, IA for routine cleaning and care, an orthodontist in Ankeny, prosthodontist at University of Illinois – Chicago, and a pediatric dentist in Iowa City.

On December 10, 2019, Alli had two temporary dental implants surgically placed in her lower anterior jaw to be used as anchors, since she doesn't have posterior teeth to use for anchorage, to correct her deep overbite and to properly make room in her mouth for the partial denture. This will also assist in correcting her crossbite and allow her to improve her ability to chew. Even though we live in the Des Moines metro area, there is not an oral surgeon that is in-network for our medical plan. We had the oral surgeon's office submit a "gap coverage request" to United Health Care in an effort to facilitate Alli's care. We were notified by our UHC Advocate that a prior authorization would be needed. The advocate reached out to the oral surgeon's office and assisted with the gap request and prior authorization. A few days prior to the December 10th surgery, we were notified by the oral surgeon's office that the prior authorization was denied as "not a covered benefit." As this was a medically-necessary surgery for Alli, we went ahead with the surgery as planned, paid $1,200 out-of-pocket, and submitted an appeal on the denied prior authorization. The claim was still submitted to our medical plan, yet it hasn't completed the review process. According to our Advocate, the claim is pending additional information from the provider's office. The outcome at this time is unknown. We plan to utilize our appeal options that our medical plan allows in an effort to obtain coverage.

Without closing the loopholes that insurance companies use to deny claims, such as "not a covered benefit" or "cosmetic," we are paying 100% out-of-pocket for our children's medical needs instead of saving money for their college tuitions or to properly invest in our retirement.

With Bennett's recent diagnosis, we currently don't know what to expect for his treatment plan. We will have frequent appointments with the specialists at the University of Iowa who are familiar with Alli, and monitor his health as he grows, and then develop a plan for his missing teeth that is age- and developmentally-appropriate for him. Our family is fortunate to have dual incomes working for great companies. Despite this, we are facing out-of-pocket expenses that could exceed our annual salaries. We need your help to make sure that families like ours, and others living with congenital anomalies have the coverage they need to live healthy and fulfilling lives. When you have a smile that you can be confident about, you can change the world! We need your help.

Karl Nelsen, PA-C, MS (47-years old), on behalf of himself and his daughter, Samantha Nelsen (9-years old), of Minnesota. My daughter, Samantha (9-years old) and I both have ectodermal dysplasia. I have been fighting for medical insurance coverage for my oral restorations my entire life. I was born with only a few baby teeth and even fewer adult teeth. I received my first set of dentures when I was 5-years old and required a new set every 2-3 years as my body grew. My parents applied for coverage through our health insurance and received denials over and over again to cover my dental prosthetics. As you can imagine, this is a stressful process, both emotionally and financially.

As I reached my 20s, my adult teeth began to fail, my dentures were not well anchored, and I had to make a major decision in my life. I pursued dental implants at the University of Minnesota. I had bone grafting, 10 implants surgically placed into my mandible and maxilla, and a new set of dental prosthetics made in order to restore my function and appearance. During the 1990s, this cost me approximately $30,000 out-of-pocket as my insurance company denied the restorative treatments on the basis that it was dental and not health-related, even though this work is clearly a restoration for a congenital defect, which was supposed to be a covered benefit. I recently collected estimates for the same work to be done. This same process is now approximately $70,000, which again would be an out-of-pocket expense for a restoration of my congenital changes.

I went approximately 20 years without being active with the National Foundation for Ectodermal Dysplasias until the birth of my daughter, Samantha Grace Nelsen, who is also affected. She is currently 9-years old and will only have a few adult teeth. She will also require dental implants just like her dad. So, the cycle will begin again. Another generation fighting with their insurance companies to get their congenital defects restored.

I believe the success of this bill is entrenched in education. One would think that medical insurance companies provide coverage for congenital defects. For the most part, they do, but our community is caught in the middle since our congenital defect affects oral structures. Thus, they automatically deny claims for our medically-necessary treatments. This is wrong, and we need to close the loopholes that insurers use to deny treatments of congenital anomalies that affect the mouth and teeth.

Julie Claeys, on behalf of her son, Carver Claeys (24-years old), of Michigan. Our son Carver is now 24 years old and completing dental implants after his whole life of wearing dentures starting at age 2 and needing a new set as he grew every two years. In order to obtain implants, Carver had to have bone taken from his hip and implanted into his jaw in order to hold implants in place to prepare for new permanent dentures.

We have paid more than $100,000 out-of-pocket because of denied claims even though our insurance plan stated that they covered medical necessity and birth defects. Congenital anomalies are supposed to be covered by our plan yet our self-funded health plan denied claims. Carver's new set of permanent dentures are billed at a cost of $40,000. He cannot eat or live healthily without these dentures that adhere to his implants. His implants are absolutely medically necessary.

Christine Gottschalk, on behalf of her son, Henry Scott (6-years old), of Washington, D.C. Our son, Henry, has Hypohidrotic Ectodermal Dysplasia, which is a congenital anomaly. Henry is giggly, tells elaborate tales about fire breathing dragons, and loves to roll down hills with his friends. He also needs teeth. One of Henry's symptoms is anodontia, or the absence of teeth. The lack of teeth impacts his nutrition, speech, and self-esteem. Recently, Henry got his first dentures, and over his lifetime, he will require complex corrective surgeries for normal function. None of the care has been approved by our health insurance. Our claims are automatically denied, and we are forced to cover these expenses out of pocket. My husband is a disabled combat veteran, and our family relies on my income and insurance for Henry's care. This means tough financial trade-offs for our family. We are saving money for teeth and other medically-necessary oral treatments instead of college and retirement, even though our insurance policy has mandated coverages for medically-necessary treatments of congenital anomalies, or when caused by an accident or illness.

Attachment 2. List of Patient and Physician Organizations Supporting the "Ensuring Lasting Smiles Act"

(In Alphabetical Order)

1. Academy of General Dentistry
2. American Academy of Dermatology Association
3. American Academy of Facial Plastic & Reconstructive Surgery
4. American Academy of Neurology
5. American Academy of Oral and Maxillofacial Pathology
6. American Academy of Oral and Maxillofacial Radiology
7. American Academy of Pediatric Dentistry
8. American Association of Oral and Maxillofacial Surgeons
9. American Association of Orthodontists
10. American Association of Women Dentists
11. American College of Prosthodontists
12. American College of Surgeons
13. American Dental Association
14. American Society of Dentist Anesthesiologists
15. American Society of Maxillofacial Surgeons
16. American Society of Plastic Surgeons
17. Bridge the Gap – SYNGAP Education & Research Foundation
18. CCD Smiles
19. Children's Hospital of Wisconsin
20. Colorado Rare
21. Costello Syndrome Family Network
22. Dermatology Nurses' Association
23. Derma Care Access Network
24. EveryLife Foundation for Rare Diseases
25. FACES: The National Craniofacial Association
26. Foundation for Ichthyosis and Related Skin Types, Inc. (FIRST)
27. Genetic Alliance
28. International Pemphigus and Pemphigoid Foundation
29. M-CM Network
30. March of Dimes
31. Moebius Syndrome Foundation
32. National Foundation for Ectodermal Dysplasias
33. National Organization for Rare Disorders
34. Noah's Hope – Hope4Bridget
35. Operation Smile
36. Pathways for Rare and Orphan Studies
37. Project Accessible Oral Health
38. Rare & Undiagnosed Network
39. rareLife Solutions
40. Soft Bones: The US Hypophosphatasia Foundation
41. SunnyStrong
42. The APS Type 1 Foundation Inc.
43. The Marfan Foundation
44. The Sturge-Weber Foundation
45. Usher 1F Collaborative
46. Virginia Council of Nurse Practitioners

Sexual Abuse to Maternal Mortality Pipeline:
https://www.govinfo.gov/content/pkg/CPRT-116HPRT46456/pdf/CPRT-116HPRT46456.pdf

[Additional submission by Ms. Stevens follows:]

nfed
Supporting you. Supporting each other.
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Jan. 27, 2020

The Honorable Frederica S. Wilson
Chair, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tim Walberg
Ranking Member, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairwoman Wilson and Ranking Member Walberg:

The National Foundation for Ectodermal Dysplasias (NFED) is the largest and only patient advocacy organization in the United States dedicated to individuals who are affected by rare genetic disorders classified as ectodermal dysplasias. The NFED's mission is to empower and connect individuals touched by ectodermal dysplasias through education, support and research. The NFED has been advocating for individuals affected by ectodermal dysplasias and all rare disorders for almost 40 years.

The ectodermal dysplasias are heritable conditions that involve defects in the hair, teeth, nails and glands. Individuals may develop only a few teeth, some develop no teeth. As you know, teeth are "medically necessary" to maintain good nutrition, speech, facial symmetry and normal growth and development. Some affected individuals can go a lifetime without teeth. There are significant medical and social implications associated with this. Children who do not develop normal teeth can suffer from failure to thrive, have speech problems, digestive disorders and many other medical problems. As a result, they have to undergo many costly medical procedures and years of costly speech therapy, all that are unnecessary if they just had teeth!

Many individuals call our office on a daily basis seeking help to get teeth for themselves or their children. Insurance companies regularly deny coverage for teeth even though most states have statutes that require such coverage of congenital defects. Insurance companies routinely deny the claims as "cosmetic". When in the world did simply having teeth become cosmetic in this country? Families are

denied coverage over and over again after years of fighting. Teeth are not cosmetic and restoration of congenital defects, including congenital dental/oral defects, should be included in all medical insurance policies. It is time for this injustice to stop.

Three years ago, the NFED embarked on a mission to advocate for federal legislation that would mandate coverage for all medically necessary restorations for ALL individuals affected by a congenital disorder. Led by a strong family advocacy committee, we have worked very hard to get legislation introduced. We found great friends and allies, Senators Tammy Baldwin and Joni Ernst and Representatives Colin Peterson and Denver Riggleman. With their dedicated support the Ensuring Lasting Smiles Act (S560 / H.R. 1379) (ELSA) was introduced as a bill in the U.S Senate and House on February 26, 2019.

Our family advocacy committee has made numerous visits to Capitol Hill and thousands of calls to legislators to garner support for this bill. We are diligent and tenacious in our efforts and we will not stop until we are successful because this is the #1 issue which most affects our community financially. People affected by ectodermal dysplasias are expected to have to pay approximately $150,000 out of pocket just for their dental care during their lives.
The NFED and our partners strongly support ELSA. Please hear our voices; listen to our pleas for equal health care for individuals who are affected by rare congenital disorders. Families are counting on you. We urge you to pass this bill in the 2020 year.

Sincerely,

Mary Fete, MSN, RN, CCM
Executive Director

Karl Nelsen, PA-C, MS
Board President

[Additional submission by Mr. Takano follows:]

Georgetown University
Health Policy Institute
CENTER FOR CHILDREN
AND FAMILIES

Medicaid Expansion Fills Gaps in Maternal Health Coverage Leading to Healthier Mothers and Babies

by Adam Searing and Donna Cohen Ross

Key Findings

- New research shows states that expand Medicaid improve the health of women of childbearing age: increasing access to preventive care, reducing adverse health outcomes before, during and after pregnancies, and reducing maternal mortality rates.
- While more must be done, Medicaid expansion is an important means of addressing persistent racial disparities in maternal health and maternal mortality.
- Better health for women of childbearing age also means better health for their infants. States that have expanded Medicaid under the Affordable Care Act saw a 50 percent greater reduction in infant mortality than non-expansion states.
- The uninsured rate for women of childbearing age is nearly twice as high in states that have not expanded Medicaid compared to those that have expanded Medicaid (16 percent v. 9 percent). States with the highest uninsured rates for women of childbearing age are: Alabama, Alaska, Florida, Georgia, Idaho, Mississippi, Nevada, North Carolina, Oklahoma, South Carolina, Texas and Wyoming. Ten of these twelve states have not expanded Medicaid.

The authors would like to thank the American College of Obstetricians and Gynecologists and the March of Dimes for their contributions to this report.

Introduction

Disruptions in health coverage are associated with adverse health consequences.[1] This is especially true for women in their childbearing years, when a pregnancy means having health coverage is even more important. The stakes are high as the care a woman receives during pregnancy is critical to her own health, as well as to the health of her newborn. In the United States, maternal and infant mortality is higher than most other industrialized nations,[2] lending urgency to strategies to address the overall health of women.[3]

In this paper we review the substantial new research showing the significant improvements in access to health coverage for women of childbearing age achieved through the adoption of the Affordable Care Act's (ACA) Medicaid expansion. Better health coverage is important not just for women who are pregnant but also for women well before they become pregnant and well after childbirth. The American College of Obstetricians and Gynecologists (ACOG) recommends women have access to continuous health coverage in order to increase preventive care, reduce avoidable adverse obstetric and gynecologic health outcomes, increase early diagnosis of disease and reduce maternal mortality rates.[4] Research also finds that Medicaid expansion has an important role in reducing the significant and persistent racial disparities in maternal and infant health. And finally, new studies show that healthier mothers mean healthier infants—another benefit for states that expand Medicaid.

Pre-ACA Medicaid Expansions Focused on Pregnancy Status

Over the past four decades, in response to concerns about high rates of infant mortality and poor birth outcomes, states have increased Medicaid eligibility for pregnant women, making health care during pregnancy significantly more accessible for lower-income women.

While this has been a positive change for both mothers and children, it is only one part of a comprehensive strategy to improve maternal and child health. It has been established that the strong connection between the health of a mother and her baby begins well before pregnancy and continues long past the 60 days of post-partum coverage Medicaid typically provides.[5] This elevates the need for overall good health throughout a woman's childbearing years. Innovative efforts such as the University of North Carolina's 4th Trimester Project, in collaboration with groups like the March of Dimes, are highlighting how increasing coverage is a key part of a comprehensive strategy to improve the health of new mothers.[6]

The Effect of State Medicaid Expansions

Reviews of state data estimate the majority of pregnancy-related deaths are preventable.[7] Expanding access to health coverage is a key strategy for addressing this problem. A growing body of research demonstrates the ACA and implementation of state Medicaid expansions have had positive effects on the health of mothers and their infants. Recent studies show that state Medicaid expansions have helped to reduce the rates of both maternal deaths and infant mortality. Women are getting better health coverage before pregnancy, leading to improved prenatal nutrition and prenatal care. And postpartum coverage has improved for women, helping them get the care they need following the birth of their child. States that have expanded Medicaid also have decreased the likelihood that eligibility for coverage will fluctuate, resulting in losing and regaining coverage over a relatively short span of time, a phenomenon known as "churning." Breaks in health coverage can disrupt care and cause existing health conditions to become more serious and more difficult and expensive to treat.[8]

Pre-ACA Medicaid Expansions for Pregnant Women and Coverage Churn for Women of Childbearing Age

In the late 1980s, prompted by high infant mortality rates, many states expanded Medicaid coverage for pregnant women. The state median income eligibility for pregnant women rose to 185 percent of the federal poverty level (FPL) by 2013 and is now 200 percent FPL.[9] Low-income parents could also obtain Medicaid coverage but at a much lower income level, typically well below 100 percent of FPL. The ACA's coverage changes, and particularly its expansion of Medicaid to both parents and adults without children in the home with incomes below 138 percent FPL, have the potential to change this situation dramatically. But the Supreme Court's decision to make Medicaid expansion optional for states, coupled with ideological objections to Medicaid expansion, led to some states rejecting the option. This has resulted in significant differences across the country in access to health coverage for women of childbearing age. (See Appendix A.)

In non-expansion states, the median Medicaid eligibility level for parents is 40 percent FPL or $8,532 per year for a family of three in 2019. This compares to a minimum parental eligibility level of 138 percent FPL ($29,435 for a family of three) in states that have expanded Medicaid.[10] And women of childbearing age who do not have children under age 19 or are currently not pregnant fare much worse in non-expansion states—they are simply not eligible for Medicaid at all unless they have a serious disability.

Such limited coverage for low-income women means coverage churn is more common in non-expansion states. Research consistently shows women of childbearing age experience high rates of transition between being covered

by different insurance providers or being covered and then becoming uninsured.[11] **While Medicaid's relatively high eligibility levels for pregnant women mean a woman's delivery is often covered, these same lower-income women are at significant risk of being uninsured in the critical months before pregnancy and after delivery.** A recent national study found that half of women who were insured by Medicaid for their delivery were uninsured prior to pregnancy.[12] And of these new mothers, 55 percent experienced another coverage gap in the six months after giving birth. The authors also note that "[t]he well-being of infants can also be negatively affected by their mothers' lack of insurance after delivery. Poor management of maternal mental health adversely affects a child's cognitive, behavioral, and socioemotional development."[13]

Table 1 shows that Medicaid expansion decisions have had a direct impact on the ability of women of childbearing age to obtain health coverage. While the ACA reduced the uninsured rate among women of childbearing age across all states, women living in states refusing the Medicaid expansion have generally experienced much smaller reductions and are more likely to remain uninsured. **States with above average declines in their uninsured rate for women of childbearing age are mainly states that have expanded Medicaid.**

States that have not expanded Medicaid generally do not cover women of childbearing age who do not have a disability if they are not pregnant or are not parents of dependent children. These states generally have extremely low eligibility levels for parents to qualify for Medicaid. For example, in Texas an income of more than $302 a month disqualifies the parents in a family of three from enrolling in Medicaid. See Table 2.

Medicaid Expansion Provides Benefits that Confer Two-Generation Advantages

ACA Medicaid expansions provide women of childbearing age their state's full benefit package for adults. These services can benefit their children, as well. For example:

- Maternal Depression Screening and Treatment. Research estimates that more than half (55 percent) of all infants in families with incomes below the poverty level are being raised by mothers with some form of depression.[a] In addition to the toll depression takes on the mother herself, it also can disrupt the formation of a strong parent-child relationship, which compromises a child's early brain development, with implications for cognitive, social and emotional health. State Medicaid programs must make depression screening without cost-sharing available to women enrolled under Medicaid expansions, and refer women at risk of perinatal depression to counseling. Many states have adopted the option to allow pediatric care providers to conduct maternal depression screenings as part of the well-child visit and also to deliver "dyadic treatment" to mother and child together.[b] In Medicaid expansion states, mothers have access to additional treatments they may need, such as more intensive therapy or medication.
- Tobacco Use Cessation. Medicaid enrollees are about twice as likely as the general U.S. population to smoke tobacco: 32 percent of beneficiaries identify themselves as smokers.[c] The ACA requires that all state Medicaid programs offer comprehensive tobacco cessation benefits without cost-sharing for pregnant women and for populations made newly eligible under Medicaid expansion. Smoking cessation can not only reduce a woman's risk of cardiovascular and respiratory disease, cancer and other chronic conditions, it also decreases the chances of pregnancy-related complications, including preterm birth, low birth weight, and sudden infant death syndrome. When adults quit smoking, they also reduce the likelihood that their children will suffer from exposure to second-hand smoke, which can trigger more frequent and severe asthma attacks and is associated with ear infections and even tooth decay.

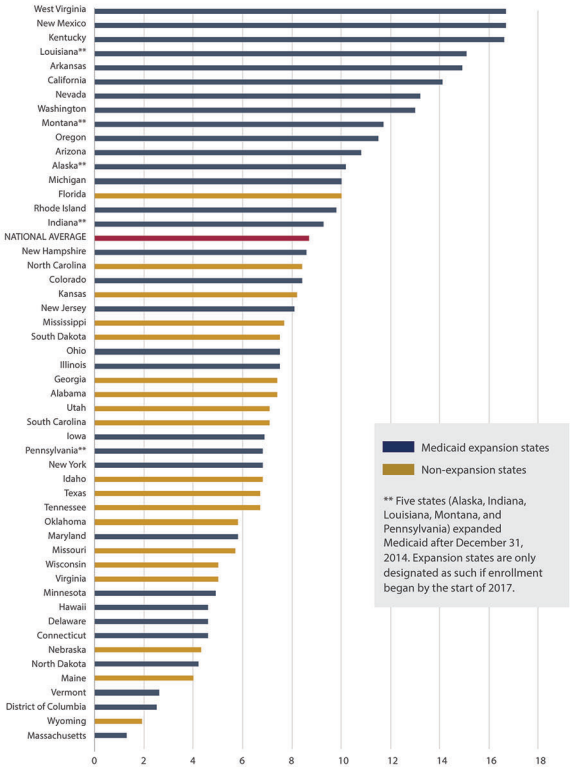
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[a] Tracey Veriker, Jennifer Macomber, and Olivia Golden, "Infants of Depressed Mothers Living in Poverty: Opportunities to Identify and Serve," The Urban Institute. August 2010.

[b] "Maternal Depression Screening and Treatment: A Critical Role for Medicaid in the Care of Mothers and Children," CMS Informational Bulletin, May 16, 2016.

[c] L. Ku, B. Bruen, S.Steinmetz, and T. Bysshe, "Medicaid Tobacco Cessation: Big Gaps Remain In Efforts To Get Smokers To Quit," Health Affairs, Vol. 35, No. 1, January 2016.

Table 1. Percentage Point Decline in the Uninsured Rate for Women of Childbearing Age (18-44), 2013-2017



Source: Data is from a Georgetown University Center for Children and Families analysis of the U.S. Census Bureau American Community Survey (ACS) data, 2013 and 2017 single year estimates from the Integrated Public Use Microdata Series (IPUMS).

Table 2. Medicaid Income Eligibility Limit in Non-Expansion States for Adults as a Percentage of the Federal Poverty Level, January 2019

State	Parent upper eligibility limit (in a family of three) – percent of FPL	Parent upper eligibility limit (in a family of three) – monthly dollar amount	Childless adult eligibility limit (for an individual)
Alabama	18%	$320	0%
Florida	32%	$569	0%
Georgia	35%	$622	0%
Idaho*	25%	$444	0%
Kansas	38%	$675	0%
Mississippi	26%	$462	0%
Missouri	21%	$373	0%
Nebraska*	63%	$1,120	0%
North Carolina	42%	$747	0%
Oklahoma	42%	$747	0%
South Carolina	67%	$1,191	0%
South Dakota	49%	$871	0%
Tennessee	95%	$1,689	0%
Texas	17%	$302	0%
Utah*	60%	$1,067	0%
Wisconsin	100%	$1,778	100%
Wyoming	54%	$960	0%

Source: Based on a national survey conducted by Kaiser Family Foundation with the Georgetown University Center for Children on Families, 2019. See here for more information on the survey and this table.

*Idaho and Nebraska voters approved Medicaid expansion but the expansions are not in effect and may be limited. Utah voters also approved a Medicaid expansion but Utah's legislature passed a law limiting the expansion to only some of those originally eligible and capping enrollment at the discretion of the state.

Note: Among reproductive-age women who remained uninsured in 2016, about 20 percent were likely eligible for comprehensive Medicaid or Children's Health Insurance Program (CHIP) coverage based on their income, indicating that outreach and enrollment efforts could help boost participation.[14]

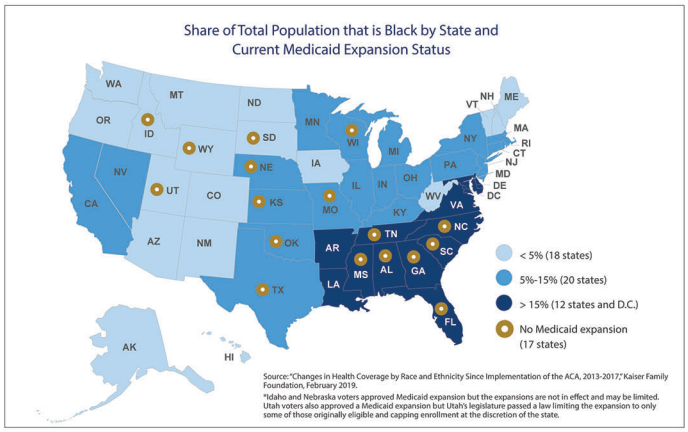
States Rejecting Medicaid Expansion are Missing an Opportunity to Address Stark Racial Disparities in Maternal Health

While strategies to increase women's health coverage have had positive effects, especially in states that have expanded Medicaid, stark racial disparities with respect to maternal mortality and maternal health persist. A recent commentary in the Journal of the American Medical Association noted that "African American women are nearly three times as likely to die of complications related to pregnancy and childbirth compared with white women . . . a gap that has not narrowed in decades."[15] The most recent comprehensive study on these disparities in the *American Journal of Obstetrics and Gynecology* found:

> "[B]lack women had a higher adjusted rate of severe maternal morbidity than white women. Our results confirm that the high risk of adverse outcomes faced by black women who give birth in comparison with white women in the United States and are similar to findings by others."[16]

Unsurprisingly, nonelderly adults are much more likely to be uninsured in states that have not expanded Medicaid.[17] Recent data specifically on women of childbearing age are not available, but overall this disparity in uninsured rates is magnified when race is taken into account. For example, the uninsured rate among nonelderly African Americans is 14 percent in states that haven't expanded Medicaid compared to 8 percent in expansion states. Nonelderly white children and adults (ages 0-64) experience lower overall rates of uninsurance: 10 percent in states that haven't expanded Medicaid compared to 6 percent in expansion states.[18] In Southern states, which make up the majority of those that have not expanded Medicaid, African Americans are disproportionately affected and experience higher uninsured rates. This is due in large part to the fact that the states that have not expanded Medicaid have larger shares of black residents.[19]

While multiple factors contribute to improving maternal health, new research is finding Medicaid coverage is a critical piece of the puzzle, especially for addressing racial inequities in access to affordable coverage and care.[20]



Source: "Changes in Health Coverage by Race and Ethnicity Since Implementation of the ACA, 2013-2017," Kaiser Family Foundation, February 2019.

*Idaho and Nebraska voters approved Medicaid expansion but the expansions are not in effect and may be limited. Utah voters also approved a Medicaid expansion but Utah's legislature passed a law limiting the expansion to only some of those originally eligible and capping enrollment at the discretion of the state.

Medicaid Expansion: Benefits for Women of Childbearing Age

When states decide to expand Medicaid, the resulting gains in coverage provide benefits that promote preventive health practices and can protect women and their children from serious health conditions and even death. Better coverage is the starting point for better care overall. In addition to the well-known advantages of being insured during pregnancy, coordination and quality of care during the pre-pregnancy period and during the postpartum period—sometimes called the "4th trimester"—are especially important.[21]

Several new studies provide insights into the impacts of Medicaid expansion for women of childbearing age including increased health coverage, earlier prenatal care, better overall care, lower rates of maternal mortality and a reduction in infant mortality.

1. Better health coverage for reproductive-age women

Overall, the ACA has had a major impact on increasing coverage for all women of reproductive age. This is due not only to Medicaid expansions but also other coverage changes like the expansion of dependent coverage to young adults up to age 26, the premium tax credit, elimination of pre-existing condition exclusions, and required coverage of maternity care. However, some low-income women are still at risk. Research published in the American Journal of Public Health reported "significant reductions in uninsurance and increases in nongroup private insurance and Medicaid among reproductive-aged women" in the first three years following the ACA's implementation. Across states, the authors identified the ACA as the cause of a 7.4 percentage-point decrease in the probability of uninsurance for reproductive age women. **Low-income women in non-expansion states were identified as a main group still at risk for lack of coverage.**[22]

2. Earlier initiation of prenatal care

The first long-term study examining the effect of pre-ACA Medicaid expansions on women of childbearing age found multiple positive effects. Medicaid expansions improved coverage prior to pregnancy and led to "earlier initiation and improved adequacy of prenatal care among pregnant mothers." Based on the findings, the author concluded that **"More recent state expansions in Medicaid under the ACA have the potential to impact even more women and children as they extend eligibility to all low-income women regardless of parental or pregnancy status."**[23]

3. Better care before women become pregnant

In Ohio, a 2018 study found that after the state's Medicaid expansion there was almost a 12 percentage-point increase in Medicaid enrollment for first-time mothers before they became pregnant. This improved access to proper prenatal care in the first 16 weeks after they became pregnant. **The researchers identified significant increases in the receipt of all recommended health screens and a nearly 14 percentage-point increase in receipt of prenatal vitamins for first-time mothers, compared with increases of 5 and 4 percentage points, respectively, for women with previous pregnancies.** Prenatal vitamins typically contain more iron and folic acid than standard adult multivitamins. They help prevent anemia during pregnancy and neural tube birth defects (such as spina bifida), which compromise a baby's brain and spinal cord development. While the authors caution the results also depend on other factors, including some unique to Ohio, the benefits for lower-income women in the state are clear after Medicaid expansion.[24]

4. Lower rates of maternal mortality

Findings from a study presented at the AcademyHealth National Health Policy Conference in February 2019 showed a link between implementation of Medicaid expansion under the ACA and lower rates of maternal mortality. An analysis of data from 1999 to 2016 from the National Center for Health Statistics compared maternal mortality rates in Medicaid expansion states with rates in states that did not expand. The study found that Medicaid expansion was associated with lower rates of maternal mortality, reflecting 1.6 fewer maternal deaths per 100,000 women. The researchers suggest that the reduction in maternal death rates is associated with women having increased access to Medicaid prior to pregnancy, which presented the opportunity to address pre-pregnancy risk factors such as obesity, diabetes and heart disease and also to begin prenatal care in a timely manner.[25]

5. Reductions in infant mortality

A study released in 2018 examined Medicaid expansions under the Affordable Care Act and their effect on the infant mortality rate in the United States. The researchers point out that since Medicaid covers a large proportion of maternal, infant, and child health care, as well as specific services related to pregnancy, maternity, pediatric care, chronic disease management, breastfeeding support, contraception, mental health and substance use disorder screening and treatment, and other behavioral health services; **"Medicaid expansion may be among the most important ways in which the ACA could improve maternal and child health indicators, such as the infant mortality rate."** Their analysis found that the infant mortality rate declined in both Medicaid expansion and non-expansion states between 2010 and 2016, however, **the decline in Medicaid expansion states was more than 50 percent greater than in non-expansion states.** The research also showed that the decline in infant mortality rates linked to Medicaid expansion were greatest among African American infants, which drove the overall decline and helped to substantially reduce the racial disparity in infant mortality rates.[26] And this improvement was not limited to overall infant mortality. Another recently released study examining the effect of state Medicaid expansions on overall birth outcomes found that while the rates of preterm birth and low birth weight did not show a change, there were significant improvements for African American infants relative to white infants. State Medicaid expansion was associated with "significant improvements in disparities for black infants relative to white infants for the four outcomes studied, including preterm birth, very preterm birth, low birth weight, and very low birth weight."[27]

Conclusion

Medicaid expansion under the Affordable Care Act offers affordable, comprehensive health coverage to women who would likely otherwise go without access to needed care. Most states have longstanding, generous Medicaid coverage for pregnant women, however, the pre-pregnancy coverage churn and post-partum (or "4th trimester") coverage gaps leave women without a full continuum of care. Prior to pregnancy, this can mean a significant missed opportunity to attend to health issues that pose high risks during pregnancy for mother and child. Similarly, a sudden plunge into uninsured status after the Medicaid post-partum period of 60 days can force women to abandon medication or other ongoing treatment they may need. And despite improved coverage during pregnancy, troubling racial maternal and infant health disparities persist, especially in Medicaid non-expansion states.

Recent studies show that Medicaid expansion has increased coverage rates for women during the childbearing years, has reduced the rate of women of childbearing age who are uninsured, and has improved health outcomes. Medicaid expansion has also played a role in reducing rates of maternal death, decreasing infant mortality rates, and improving the potential for optimal birth outcomes that can increase the prospects for a healthy childhood. Finally, it is clear if the remaining non-expansion states want to address significant racial disparities in maternal and infant health, expanding Medicaid is a critical first step.

Additional research could further illuminate the value of Medicaid expansion for women and their children. Many of the benefits Medicaid provides—smoking cessation treatment, treatment for substance use disorders, maternal depression screening and treatment, oral healthcare and other benefits—are likely to have positive two-generation impacts on women and their children.

Appendix A. Medicaid Income Eligibility Limit for Adults as a Percent of the FPL, January 2019

State	Parent upper eligibility limit (in a family of three) – percent of FPL	Parent upper eligibility limit (in a family of three) – monthly dollar amount	Childless adult eligibility limit (for an individual)
Alabama	18%	$320	0%
Alaska	138%	$3,066	138%
Arizona	138%	$2,453	138%
Arkansas	138%	$2,453	138%
California	138%	$2,453	138%
Colorado	138%	$2,453	138%
Connecticut	155%	$2,755	138%
Delaware	138%	$2,453	138%
District of Columbia	221%	$3,928	215%
Florida	32%	$569	0%
Georgia	35%	$622	0%
Hawaii	138%	$2,822	138%
Idaho*	25%	$444	0%
Illinois	138%	$2,453	138%
Indiana	139%	$2,471	139%
Iowa	138%	$2,453	138%
Kansas	38%	$675	0%
Kentucky	138%	$2,453	138%
Louisiana	138%	$2,453	138%
Maine**	138%	$2,453	138%
Maryland	138%	$2,453	138%
Massachusetts	138%	$2,453	138%
Michigan	138%	$2,453	138%
Minnesota	138%	$2,453	138%
Mississippi	26%	$462	0%
Missouri	21%	$373	0%
Montana	138%	$2,453	138%
Nebraska*	63%	$1,120	0%
Nevada	138%	$2,453	138%
New Hampshire	138%	$2,453	138%
New Jersey	138%	$2,453	138%
New Mexico	138%	$2,453	138%
New York	138%	$2,453	138%
North Carolina	42%	$747	0%
North Dakota	138%	$2,453	138%
Ohio	138%	$2,453	138%
Oklahoma	42%	$747	0%
Oregon	138%	$2,453	138%
Pennsylvania	138%	$2,453	138%
Rhode Island	138%	$2,453	138%
South Carolina	67%	$1,191	0%
South Dakota	49%	$871	0%
Tennessee	95%	$1,689	0%
Texas	17%	$302	0%
Utah*	60%	$1,067	0%
Vermont	138%	$2,453	138%
Virginia**	138%	$2,453	138%
Washington	138%	$2,453	138%
West Virginia	138%	$2,453	138%
Wisconsin	100%	$1,778	100%
Wyoming	54%	$960	0%

Non-expansion states

Source: Based on a national survey conducted by Kaiser Family Foundation with the Georgetown University Center for Children on Families, 2019. See here and here for more information on the survey and this table.

* Idaho and Nebraska voters approved Medicaid expansions but the expansions are not in effect and may be limited.

** Medicaid expansions in Maine and Virginia did not go into effect until 2019.

Appendix B. Uninsured Rates by State for Women of Child-Bearing Age (18-44), Comparing Rates for 2013 and 2017

Region	Uninsured Percent 2013 for Women Ages 18-44	Uninsured Percent 2017 for Women Ages 18-44	Percentage Point Change 2013-2017
US Total	21.0	12.3	-8.7
Alabama	23.0	15.6	-7.4
Alaska	25.5	15.3	-10.2
Arizona	24.2	13.4	-10.8
Arkansas	26.3	11.4	-14.9
California	23.4	9.3	-14.1
Colorado	18.6	10.2	-8.4
Connecticut	12.1	7.5	-4.6
Delaware	12.7	8.1	-4.6
District of Columbia	5.5	3.0	-2.5
Florida	29.0	19	-10.0
Georgia	27.5	20.1	-7.4
Hawaii	9.8	5.2	-4.6
Idaho	24.4	17.6	-6.8
Illinois	17.2	9.7	-7.5
Indiana	21.0	11.7	-9.3
Iowa	12.7	5.8	-6.9
Kansas	20.2	12.0	-8.2
Kentucky	24.0	7.4	-16.6
Louisiana	25.9	10.8	-15.1
Maine	15.8	11.8	-4.0
Maryland	13.9	8.1	-5.8
Massachusetts	4.6	3.3	-1.3
Michigan	16.4	6.4	-10.0
Minnesota	10.8	5.9	-4.9
Mississippi	26.2	18.5	-7.7
Missouri	19.6	13.9	-5.7
Montana	23.7	12.0	-11.7
Nebraska	16.8	12.5	-4.3
Nevada	29.0	15.8	-13.2
New Hampshire	16.5	7.9	-8.6
New Jersey	19.7	11.6	-8.1
New Mexico	29.8	13.1	-16.7
New York	14.2	7.4	-6.8
North Carolina	24.1	15.7	-8.4
North Dakota	14.4	10.2	-4.2
Ohio	15.1	7.6	-7.5
Oklahoma	27.2	21.4	-5.8
Oregon	20.8	9.3	-11.5
Pennsylvania	13.9	7.1	-6.8
Rhode Island	15.8	6.0	-9.8
South Carolina	23.9	16.8	-7.1
South Dakota	19.8	12.3	-7.5
Tennessee	18.9	12.2	-6.7
Texas	32.2	25.5	-6.7
Utah	18.3	11.2	-7.1
Vermont	8.0	5.4	-2.6
Virginia	17.4	12.4	-5.0
Washington	21.4	8.4	-13.0
West Virginia	24.6	7.9	-16.7
Wisconsin	11.8	6.8	-5.0
Wyoming	19.4	17.5	-1.9

Source: Data is from a Georgetown University Center for Children and Families analysis of the U.S. Census Bureau American Community Survey (ACS) data, 2013 and 2017 single year estimates from the Integrated Public Use Microdata Series (IPUMS).

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Written by Adam Searing and Donna Cohen Ross. The authors would like to thank Joan Alker and Catherine Hope for their contributions to this brief. Design and layout provided by Nancy Magill.

The Georgetown University Center for Children and Families (CCF) is an independent, nonpartisan policy and research center founded in 2005 with a mission to expand and improve high-quality, affordable health coverage for America's children and families. CCF is based in the McCourt School of Public Policy's Health Policy Institute.

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[Additional submissions by Ms. Underwood follow:]

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To the honorable Chairwomen Frederica Wilson and Alma Adams, Ranking Member Tim Walberg, and Ranking Member Bradley Byrne:

Mom Congress - a mother's rights movement representing moms from all 50 states who advocate for improvements in maternity care, maternal mental healthcare, and paid family leave policies - applauds the recent hearing, *Expecting More: Addressing America's Maternal and Infant Health Crisis,* in front of the House Health, Employment, Labor, and Pensions Subcommittee and Workforce Protections Subcommittee on January 28th. We thank the participating Congress Members for acknowledging the unacceptably high US maternal mortality rates - which have more than doubled from 1987 to 2016 - in contrast to declining maternal death rates in other developed nations. **We urge you to make policy changes to support quality maternal healthcare - both physical and mental** - in honor of the 700 mothers who die and 50,000 mothers who suffer from life-threatening pregnancy-related complications in the US each year. We thank you for highlighting the need to eliminate racial disparities in care in response to alarming data showing that women of color are 3 times as likely to die of a pregnancy-related complication as white women.

One important issue that we would like to bring to the Congressional Committees' attention is the **contribution of maternal mental health (MMH) disorders - such as prenatal and postpartum depression and anxiety - to maternal mortality**. MMH disorders represent the #1 complication of pregnancy[1] and affect up to 800,000 US mothers annually. Suicide is reported as the 7th leading cause (7%) of pregnancy-related deaths[2], but the American College of Obstetrics & Gynecology (ACOG) is concerned that deaths caused by MMH disorders are under-reported nationally[3]. Studies show that self-harm - which is associated with MMH disorders, and includes both suicides and drug overdoses - accounts for far more maternal deaths than previously estimated (up to 30% in some states). [4] [5] [6]

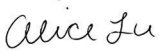
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Mom Congress supports the range of strategies discussed at the January 28th hearing to improve maternal healthcare, including quality improvement initiatives for maternity care; extending Medicaid coverage for childbearing mothers to 1 year postpartum; reducing cost-sharing requirements for prenatal and postpartum care; combating racism and implicit bias against mothers of color; and increasing access to midwifery services in areas with obstetric shortages. It's critical that the federal government create policy that measures and holds hospitals and OB / GYNs accountable for immediate adoption of clinician practice guidelines and measures compliance rates.

Finally, we thank the Committees for recognizing the need for a paid family leave policy so that mothers can recover from childbirth, have time to bond with their babies, and lower their risk of MMH disorders. 6 in 10 mothers work, representing the fastest-growing segment of the US workforce. Unfortunately, nearly one quarter of new moms return to work within 2 weeks after childbirth - before they have fully healed - because they can not afford to go without an income. The health of U.S. families depends on physically and mentally healthy moms - and paid leave can ensure that mothers have the time to care for their babies and themselves when they have a serious health condition.

Best Regards,



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Written Testimony

Of

The American College of Obstetricians and Gynecologists

Before the

House Committee on Education and Labor

Regarding the Hearing

Expecting More: Addressing America's Maternal and Infant Health Crisis

January 28, 2020

Chairman Scott, Ranking Member Foxx, and distinguished members of the Education and Labor Committee, thank you for the opportunity to submit this statement for the Committee's record of its hearing entitled "Expecting More: Addressing America's Maternal and Infant Health Crisis". The American College of Obstetricians and Gynecologists (ACOG), with a membership of more than 60,000, is the leading physician organization dedicated to advancing women's health. Key to that mission is our core value that all women should have access to affordable, high-quality, safe health care.

As members of the Committee know, and the title of this hearing reinforces, the United States is in crisis. More than 700 women die each year in the United States from pregnancy-related or pregnancy-associated complications.[1] The U.S. has a higher maternal mortality rate than any other industrialized country. At a time when 157 of 183 countries in the world report decreases in rates of maternal mortality, ours is rising.[2]

According to the Centers for Disease Control and Prevention (CDC), over 60 percent of maternal deaths are preventable.[3] Common causes include hemorrhage, cardiovascular and coronary conditions, cardiomyopathy, and infection. Overdose and suicide, driven primarily by the opioid epidemic, are also emerging as leading causes of maternal mortality in a growing number of states.[4]

Non-Hispanic Black women experience three to four times the rate of maternal mortality than non-Hispanic White women and disparities persist even when controlling for socioeconomic status.[5] Native American/Alaska Native women are two to three times more likely to experience a pregnancy-related mortality.[6] For every maternal death in the United States, there are 100 women who experience severe maternal morbidity, or a "near miss". These numbers are unacceptable. ACOG is committed to our goal of eliminating preventable maternal deaths and to eliminating the unacceptable racial disparities in maternal health outcomes. We are eager to continue our strong partnership with this Committee and other valuable partners to achieve this important goal.

We applaud you and your colleagues in the US Congress for taking an important first step last Congress in passing the Preventing Maternal Deaths Act, P.L. 115-344, to encourage states to create and expand maternal mortality review committees (MMRCs). MMRCs are multidisciplinary groups of state experts in maternal and public health, as well as community advocates, that review individual maternal deaths and identify actionable recommendations to reduce preventable maternal deaths. While traditional public health surveillance using vital

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[1] *Building U.S. Capacity to Review and Prevent Maternal Deaths.* (2018). Report from nine maternal mortality review committees. Retrieved from http://reviewtoaction.org/Report_from_Nine_MMRCs
[2] *Reducing Maternal Mortality in the United States.*Lu MC. JAMA. Published online September 10, 2018. doi:10.1001/jama.2018.11652
[3] *Building U.S. Capacity to Review and Prevent Maternal Deaths.* (2018). Report from nine maternal mortality review committees. Retrieved from http://reviewtoaction.org/Report_from_Nine_MMRCs
[4] Ibid.
[5] *Pregnancy Mortality Surveillance System*. Centers for Disease Control and Prevention. Available at: https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html
[6] *Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017.* Petersen EE, Davis NL, Goodman D, et al. MMWR Morb Mortal Wkly Rep 2019;68:423–429. DOI: http://dx.doi.org/10.15585/mmwr.mm6818e1

statistics can tell us about trends and disparities, MMRCs are best positioned to comprehensively assess and characterize maternal deaths, to understand the causes and contributing factors and identify opportunities for prevention.

Eliminating racial disparities in maternal health outcomes

We need action and policies that work to eliminate preventable maternal mortality and that seek to eliminate unacceptable racial disparities in maternal health outcomes.

At ACOG, we are committed to addressing implicit bias, structural racism, and increasing the provision of culturally competent care. Our Committee Opinion No. 649 *Racial and Ethnic Disparities in Obstetrics and Gynecology* calls upon obstetrician–gynecologists and other health care practitioners to "acknowledge the role they play in perpetuating health care disparities" and to "advocate for a system of more culturally and linguistically appropriate care for all."[7]

ACOG is working with our partners at the National Birth Equity Collaborative and the California Maternal Quality Care Collaborative to eliminate preventable maternal mortality by raising up the voices and experiences of Black women through Mother's Voices Driving Birth Equity, a project funded by the Robert Wood Johnson Foundation. This work is being led by Black scholars to better understand Black women's birth experiences in different geographic regions. Through this project, we will be able to incorporate patient voices and lived experiences in our patient safety work. If we hope to change how care is delivered, we must ensure that the methods hospitals and clinicians use to address implicit bias and racism align with Black women's needs, values, and preferences.

In partnership with the U.S. Health Resources and Services Administration (HRSA), ACOG is also working to reduce maternal mortality and eliminate disparities in outcomes through the Alliance for Innovation on Maternal Health (AIM). AIM is a national, cross-sector, data-driven maternal safety and quality improvement initiative focused on increasing and supporting the adoption of evidence-based maternal safety best practices to promote safe maternal healthcare for every U.S. birth. AIM assists state-based teams and health systems with the implementation of maternal safety bundles. These bundles seek to improve the quality and safety of maternity care with the goal of reducing maternal deaths and severe maternal morbidity, including the stark racial and ethnic disparities in maternal health outcomes, by engaging health care organizations, state-based public health systems, consumer and patient advocacy groups, and other stakeholders within a national partnership to assist state-based teams in implementing evidence-based maternal safety best practices. The Reduction in Peripartum Disparities Bundle outlines best practices for physicians and health professionals to implement to address disparities in outcomes.

At ACOG, we are committed to addressing implicit bias, structural racism, and increasing the provision of culturally competent care to our patients and we urge Congress to support legislation to help combat this crisis.

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[7] *Racial and ethnic disparities in obstetrics and gynecology*. Committee Opinion No. 649. American College of Obstetricians and Gynecologists. Obstet Gynecol 2015;126:e130–4.

Support for workplace accommodations for breastfeeding mothers

ACOG strongly supports breastfeeding as the preferred method of feeding for newborns and infants and recommends exclusive breastfeeding until the infant is approximately six months of age, with continued breastfeeding as complementary foods are introduced during the infant's first year of life, or longer, as mutually desired by the woman and her infant. [8] Enabling women to breastfeed is a public health priority. Interruption of lactation is associated with adverse health outcomes for infants, including greater infant risk of infectious disease, sudden infant death syndrome, and metabolic disease. Equally important, there are long term adverse health implications for maternal health, including higher maternal risks of breast cancer, ovarian cancer, diabetes, hypertension, and heart disease. Maintaining milk supply depends largely on frequency of milk removal through breastfeeding and through expressing milk (breast pumping or manual expression) when the woman and her infant are separated. Policies that protect the right of a woman and her child to breastfeed in public and that accommodate milk expression, such as insurance coverage for breast pumps, paid maternity leave, on-site childcare, break time for expressing milk, and a clean, private location for expressing milk, are essential to sustaining breastfeeding.[9]

While the Patient Protection and Affordable Care Act (ACA) amended the Fair Labor Standards Act to require employers to provide a nursing mother reasonable break time and a place that is shielded from view and free from intrusion to express milk for one year after childbirth, a gap in the law allows for the exclusion of 9 million employees from these workplace accommodations, including salaried employees, such as teachers. ACOG supports H.R. 5592, the Providing Urgent Maternal Protections for Nursing Mothers Act, which would close this gap by extending the ACA's workplace protections to cover salaried employees and others currently exempt from protections. We urge swift passage of this bill to ensure that nursing mothers have adequate protections in the workplace.

Importance of coverage for prenatal and maternity care

ACOG strongly believes that essential maternity care benefits, including prenatal care, should be guaranteed for all women, regardless of where they get their coverage; maternity coverage should be uniform and affordable under all insurance; and pregnancy and preventative care should be offered without cost-sharing.[10] ACOG supports a core package of benefits for all women, regardless of their health, age, employment status, or where they live. All coverage sources, including employer-sponsored, individually purchased insurance, insurance obtained as a dependent, and public programs, should comply with this essential benefit standard. Out-of-pocket expenses should be minimized, and women should not be charged higher premiums than men for equivalent services.

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[8] *Optimizing support for breastfeeding as part of obstetric practice.* ACOG Committee Opinion No. 756. American College of Obstetricians and Gynecologists. Obstet Gynecol 2018;132:e187–96.
[9] Ibid.
[10] *Women's Health in Health Care Reform: Essential Insurance Reforms.* ACOG Department of Government Relations and Outreach. April 2009. Retrieved from: https://www.acog.org/-/media/Departments/Members-Only/Government-Relations-and-Outreach/2017-Health-Care-Reform/2010EssentialInsuranceReforms.pdf?dmc=1

With the standardized cost of maternity care being $29,314,[11] it is clear the only way women can afford maternity care is with health insurance. Uninsured women face even greater costs without access to free prenatal care. However, even for women who are insured, coverage may not be sufficient to cover the cost of maternity care. According to a Kaiser Family Foundation analysis, many middle class families do not have the resources to meet the deductibles in private health plans.[12] A recent study showed that between 2008 and 2015, average out-of-pocket spending for maternity care rose among women with employer-based coverage even though the overall cost of maternity care remained stable.[13] The authors concluded that women with deductibles were paying for a higher proportion of maternity care services over time. Unfortunately, with more than half of births in the U.S. being unplanned,[14] what a woman needs in a health plan mid-year can suddenly be very different from what it was during open enrollment if she wasn't planning on getting pregnant. Switching health plans can provide the financial protection pregnant women and their families need during this life-changing period.

Although the ACA has added many protections for pregnant women, including making maternity care an Essential Health Benefit and requiring plans to cover prenatal care with no cost-sharing, it should go further by allowing women to pick and switch plans with lower out-of-pocket costs when they become pregnant.

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As our testimony outlines, the United States is in crisis and swift policy solutions are needed to help combat a rising maternal mortality rate, and eliminate unacceptable racial disparities. As Congress considers actions to take in the 116th Congress, ACOG urges you to prioritize passage of H.R. 4995, the Maternal Health Quality Improvement Act, and H.R. 4996, the Helping Medicaid Offer Maternity Services Act. These bills are critically important eliminating preventable maternal deaths.

H.R. 4995 would accelerate evidence-based patient safety changes and move the needle in maternal mortality by:

- **Authorizing the Alliance for Innovation on Maternal Health (AIM) program, to help ensure implementation of best practices and eliminate preventable maternal mortality and severe maternal morbidity for every U.S. birth.** The *Maternal Health Quality Improvement Act* would authorize the AIM program, an initiative of the Health Resources Services Administration (HRSA), and provide support to advance evidence-

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[11] *Out-Of-Pocket Spending For Maternity Care Among Women With Employer-Based Insurance, 2008–2015.* Moniz, MH, Fendrick, AM, Kolenic, GE, et al., Health Affairs Blog. Vol. 39, No. 1. Retrieved from: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2019.00296

[12] *Consumer Assets and Patient Cost Sharing.* Claxton, G, Rae, M, Panchal, Nirmita. Kaiser Family Foundation. February 2015. Retrieved from: http://files.kff.org/attachment/issue-brief-consumer-assets-and-patient-cost-sharing

[13] *Out-Of-Pocket Spending For Maternity Care Among Women With Employer-Based Insurance, 2008–2015.* Moniz, MH, Fendrick, AM, Kolenic, GE, et al., Health Affairs Blog. Vol. 39, No. 1. Available at: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2019.00296

[14] *Unintended Pregnancy in the United States.* Guttmacher Institute. January 2019. Available at: https://www.guttmacher.org/fact-sheet/unintended-pregnancy-united-states

based practices to improve the quality and safety of maternity care throughout the care continuum.

- **Addressing racial and ethnic health disparities through implicit bias training and increasing the provision of culturally competent care.** Research suggests that stereotyping and implicit bias on the part of health care providers can contribute to racial and ethnic disparities in health outcomes.[15] Providing support for training programs to eliminate and prevent discrimination in the provision of health care services can combat implicit biases and improve cultural competency in provider-patient communications and the provision of care.
- **Supporting state-based perinatal quality collaboratives working with providers, hospitals, and public health officials to implement best practices.** With the *Preventing Maternal Deaths Act,* Congress made a significant commitment to discovering the drivers of maternal mortality and identifying opportunities to prevent future tragedies. However, the investment in state Maternal Mortality Review Committees (MMRCs) is only beneficial if the data gathered leads to meaningful and timely action. Perinatal quality collaboratives (PQCs) – networks of health care providers, systems, public health professionals and other stakeholders – translate MMRC recommendations into policy and health care practice changes that will save women's lives. For years, state-based PQCs have improved health outcomes for women and infants and lowered health care costs. For example, from September 2008 to March 2015, Ohio's PQC achieved an estimated cost savings of over $27,789,000 associated with a shift of 48,400 births to 39 weeks gestation or greater and a 68% decline in the rate of deliveries at less than 39 weeks gestation without a medical indication.[16] Appropriately resourced, PQCs can provide the network and infrastructure to facilitate system-wide implementation of MMRC recommendations.
- **Improving access to obstetric care in rural areas through the creation of rural obstetric network grants, enhanced data collection, and telehealth programs.** Women living in rural areas have less health care access and experience poorer health outcomes than women living in urban areas,[17] a trend exacerbated by the rapid rate of rural hospital closures and shuttering of obstetric units. Establishing rural obstetric networks, training providers in rural communities, and expanding access to telehealth services will help close the access gap for the approximately 500,000 women who give birth each year in rural hospitals. [18]

H.R. 4996 is also critical to eliminating preventable maternal deaths by allowing states the option to extend continuous Medicaid or CHIP eligibility for women for one year postpartum. Medicaid is the largest single payer of maternity care in the U.S., covering 42.6%

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[15] *Racial and ethnic disparities in obstetrics and gynecology.* Committee Opinion No. 649. American College of Obstetricians and Gynecologists. Obstet Gynecol 2015;126:e130–4. https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Racial-and-Ethnic-Disparities-in-Obstetrics-and-Gynecology

[16] *About Perinatal Quality Collaboratives.* Centers for Disease Control and Prevention. Available at: https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc.htm#success

[17] *Health disparities in rural women.* Committee Opinion No. 586. American College of Obstetricians and Gynecologists. Obstet Gynecol 2014;123:384–8.

[18] *As Rural Hospitals Struggle, Some Opt To Close Labor And Delivery Units.* Andrews, M. Kaiser Health News (2016, February 23). Retrieved from https://khn.org/news/as-rural-hospitals-struggle-some-opt-to-close-labor-and-delivery-units/

of births.[19] However, Medicaid pregnancy coverage ends roughly 60-days postpartum. As many MMRCs have found, and the CDC has confirmed, about 33% of pregnancy-related deaths occur during the time between 7 days to one year following childbirth, and greater than one third of those deaths occurred 43-365 days postpartum.[20] Deaths from preventable causes, including overdose and suicide, occur more frequently during this 12-month postpartum period.[21] Closing this critical gap in coverage during this vulnerable time can mean the difference between life and death for many mothers. The *Helping Medicaid Offer Maternity Services Act* represents a positive step forward, and we urge its swift passage.

Thank you for the opportunity to provide testimony. With the help of this Committee, we can continue to make significant and meaningful progress on the path to better maternal outcomes. We look forward to working together with you to eliminate preventable maternal mortality and the unacceptable racial disparities in maternal health outcomes. Through this work, we can improve the lives of women, families, and communities.

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[19] *Births: Final Data for 2016*. National vital statistics reports; Martin JA, Hamilton BE, Osterman MJK, Driscoll AK, and Drake P. (2018, January 31) vol 67 no 1. Hyattsville, MD: National Center for Health Statistics. Retrieved from https://www.cdc.gov/nchs/data/nvsr/nvsr67/nvsr67_01.pdf.

[20] *Vital Signs:* Pregnancy-Related Deaths, United States. Petersen EE, Davis NL, Goodman D, et al., 2011–2015, and Strategies for Prevention, 13 States, 2013–2017. MMWR Morb Mortal Wkly Rep 2019;68:423–429. DOI: http://dx.doi.org/10.15585/mmwr.mm6818e1.

[21] *For Addicted Women, the Year After Childbirth Is the Deadliest.* Vestal, Christine. (2018, August 14) Pew Stateline. Retrieved from https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/08/14/for-addicted-women-the-year-after-childbirth-isthe-deadliest.



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To the Honorable Chairwomen Frederica Wilson and Alma Adams, Ranking Member Tim Walberg, and Ranking Member Bradley Byrne:

2020 Mom - a non-profit organization dedicated to closing gaps in maternal mental healthcare through policy, practice, and system change - would like to thank the House Health, Employment, Labor, and Pensions Subcommittee and Workforce Protections Subcommittee for holding the recent hearing, *Expecting More: Addressing America's Maternal and Infant Health Crisis,* on January 28th.

An under-recognized issue that we would like to bring to the Congressional Committees' attention is the significant **contribution of maternal mental health (MMH) disorders - such as prenatal and postpartum depression and anxiety - to maternal mortality**. Suicide is the 7th leading cause (7%) of pregnancy-related deaths[1], with devastating effects on the children and families that are left behind without a mother. Moreover, studies have shown that self-harm - which is associated with MMH disorders, and includes drug overdoses in addition to suicides - accounts for a far greater proportion of maternal deaths.[2] [3] The Colorado Maternal Mortality Review Committee performed an extensive review corroborating medical and mental health records with police / coroner reports, and found that self-harm represented 30% of maternal deaths[4] - as THE leading cause of death in the state during or within a year of pregnancy - far surpassing cardiovascular conditions, hemorrhage, and infection combined (18%), the leading physical causes of maternal deaths. Similarly, self-harm accounted for 20% of postpartum deaths in California[5]. Our concern is that deaths caused by MMH disorders are vastly under-

[1] CDC Foundation, Report from Nine Maternal Mortality Review Committees: Building US Capacity to Review and Prevent Maternal Deaths. Review to Action, 2019 May.
[2] Mangla, K. Maternal Mortality May Be Higher Than We Thought. Columbia University Irving Medical Center blog post, 2019 May 14.
[3] Mangla K, et al. Maternal Self-Harm Deaths: An Unrecognized and Preventable Outcome. Am J Obstet Gynecol. 2019 Oct.
[4] Metz, T. et al. Maternal Deaths from Suicide and Overdose in Colorado, 2004-2012. *Obstet Gynecol.* 2016 December; 128(6): 1233–1240. doi:10.1097/AOG.0000000000001695.
[5] Goldman-Mellor, S. et al. Maternal Drug-Related Death and Suicide are Leading Causes of Postpartum Deaths in California. 2019 Nov; *American Journal of Obstetrics & Gynecology*. 221(5): 489.e1-488.e9.

reported as pregnancy-related on a national basis, even though MMH disorders represent the #1 complication of pregnancy[6] and affect up to 800,000 US mothers annually. The American College of Obstetrics & Gynecology recently issued a statement[7] reinforcing the need to better track maternal deaths from suicide and substance use disorders within 12 months postpartum in response to the US maternal mortality data released by the CDC.

MMH disorders are also a leading cause of severe maternal morbidity. In a study following 3 million births in California and Florida, the rate of hospitalization and ER visits for mothers who developed severe depression was 36.7 / 10,000 deliveries within 40 weeks postpartum[8]. If this rate is consistent across the US, postpartum depression-related hospitalizations would represent the 2nd leading indicator of severe childbirth-related complications - far more prevalent than sepsis (5.2 / 10,000 deliveries) and eclampsia (3.2 / 10,000 deliveries)[9].

We urge our legislators not to overlook the uncomfortable truth that MMH disorders are a leading cause of maternal deaths and hospitalizations during pregnancy and the postpartum period. We owe it to US mothers and their families to create policy changes to address MMH disorders.

Best Regards,



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[6] Postpartum Support International website, accessed 2020 Feb 4. https://www.postpartum.net/learn-more/depression-during-pregnancy-postpartum/
[7] ACOG Press Release, 2020 Jan 30. https://m.acog.org/About-ACOG/News-Room/Statements/2020/Standardized-Maternal-Mortality-Data-Critical-Step-in-Eliminating-Preventable-Maternal-Deaths
[8] Franca, U. et al. Frequency, Trends, and Antecedents of Severe Maternal Depression After 3 Million US Births. PLoS ONE, 2018 Feb 14; 13(2): e0192854.
[9] Fingar, K. et al. Trends and Disparities in Delivery Hospitalizations Involving Severe Maternal Morbidity, 2006–2015. AHRQ's Healthcare Cost and Utilization Project, Statistical Brief #243, 2018 September.

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Eliminating Racial Disparaities In Maternal and Infant Mortality:
https://www.govinfo.gov/content/pkg/CPRT-116HPRT46460/pdf/CPRT-116HPRT46460.pdf

[Additional submissions by Chairwoman Wilson follow:]

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January 27, 2020

The Honorable Frederica S. Wilson
Chair, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tim Walberg
Ranking Member, Health, Employment, Labor, and Pensions Subcommittee
House Committee on Education and Labor
2181 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairwoman Wilson and Ranking Member Walberg:

On behalf of our 163,000 members, we are writing to thank you for holding a hearing on H.R. 1379, the Ensuring Lasting Smiles Act. As the nation's oldest and largest dental professional organization, the American Dental Association (ADA) strongly supports this bipartisan legislation.

As you know, the Ensuring Lasting Smiles Act would require all private group and individual health plans to cover medically necessary services resulting from a congenital anomaly or birth defect. One in every 33 children in the United States is born with a congenital anomaly or birth defect that affects the way they look, develop or function. This legislation is crucial to ensure that children suffering from congenital anomalies and birth defects are able to receive the treatment they need.

Many of these congenital anomalies include severe oral and facial defects such as cleft lip or palate, skeletal and maxillofacial deformities, hypodontia (absence of teeth), and enamel hypoplasia. These anomalies can interfere with a child's ability to breathe, speak, and/or eat in a normal manner. Specialized surgery is needed to correct these anomalies. These procedures are reconstructive in nature and are performed to correct abnormal structures of the body.

Despite this, many insurance companies consider these services to be cosmetic, and while they may cover the preliminary surgeries, they will delay or deny follow-up or corrective procedures, including dental work related to the anomaly. This can further delay a child's developmental milestones.

Passage of H.R. 1379 would help patients with craniofacial anomalies, and would also ensure they have the necessary coverage to restore their ability to function. On behalf of our

members and their patients, we would like to thank you for considering this important legislation. Please contact Ms. Natalie Hales at (202) 898-2404 or halesn@ada.org with any questions.

Sincerely,

Chad P. Gehani, D.D.S.
President

Kathleen T. O'Loughlin, D.M.D., M.P.H.
Executive Director

GPO:KTO:nh

WILSON

Statement of the American Society of Plastic Surgeons

Before the House of Representatives Education and Labor Committee
Subcommittee on Health, Employment, Labor, and Pensions
Subcommittee on Workforce Protections

"Expecting More: Addressing America's Maternal and Infant Health Crisis"

January 28, 2020

Chairwoman Wilson, Chairwoman Adams, Ranking Member Walberg, Ranking Member Byrne, and members of the Subcommittees, the American Society of Plastic Surgeons thanks you for holding today's hearing to focus on health issues impacting women and children. As the committee considers these important issues, we would like to highlight legislation to address congenital anomalies, the *Ensuring Lasting Smiles Act* (ELSA), H.R. 1379.

The American Society of Plastic Surgeons (ASPS) is the largest association of plastic surgeons in the world, representing more than 7,000 members and 93 percent of all board-certified plastic surgeons in the United States. Our mission is to advance quality care for plastic surgery patients and promote public policy that protects patient safety and ensures appropriate access.

For more than two decades, the ASPS has championed federal legislation advocating for access to care for individuals with congenital anomalies. Our members work with children and families to ensure appropriate insurance coverage and see first-hand the challenges and long-term impact of denials or delays in coverage. ASPS first worked on the *Treatment of Children's Deformities Act* introduced in 1998 during the 105th Congress. The legislation has enjoyed broad, bipartisan support and in fact was included in the House of Representatives *Patient Protection and Affordable Care Act* during the 111th Congress. The legislation, then titled *Children's Access to Reconstructive Evaluations and Surgery (CARES) Act*, was part of a bipartisan package of non-controversial amendments considered and accepted during the ACA markup in the House Energy and Commerce Committee. Although the House version of the ACA did not become law, the bipartisan work in this area helped to realize a uniform definition for reconstructive surgery which importantly clarifies that "follow up treatment needed to correct or improve a part of the body because of birth defects, accidents, injuries or medical conditions" is included.

Although many states have acted to clarify coverage in areas such as cleft lip and cleft palate, federal legislation is necessary to ensure that ERISA plans ensure access. Congenital anomalies often require multi-stage procedures to approximate a normal appearance and timely intervention is important to a child's development.

The Centers for Disease Control and Prevention (CDC) classifies birth defects as "common, costly, and critical" and reports that one in 33 newborns in the United States suffers from a congenital anomaly. Of the 120,000 children born annually with a congenital anomaly, approximately 40,000 require reconstructive surgery. Craniofacial anomalies can restrict a child's ability to breathe, eat, and speak in a normal manner. Therefore, surgery to repair an anomaly – which is highly individualized – is intended to help a child obtain the ability to function and grow normally. Early intervention by a team of specialists, including plastic surgeons, is necessary to assess and oversee the patient's treatment and development, sometimes over the course of several years.

Examples of these anomalies include cleft lip; cleft palate; skin lesions; vascular anomalies; malformations of the ear, hand, or foot; and other more profound craniofacial conditions. On average, children with congenital or developmental anomalies can expect anywhere from three to five surgical procedures before normalcy and function are achieved. Although surgeons can correct many of these problems, some insurance companies deny access to care by labeling the procedures "cosmetic" or "non-functional" in nature. However, the American Medical Association defines surgery performed on abnormal structures of the body caused by congenital defects or developmental abnormalities as reconstructive – not cosmetic. Denial or delay of these procedures – which by definition are reconstructive – could lead to long-term physical and psychological injuries. Furthermore, insurers frequently overlook the dental and orthodontic needs of these patients – which are essential to their achieving normal form and function – and mislead affected patients and the public when deeming these procedures cosmetic. When private insurance denies a child's reconstructive surgery, families many times end up turning to Medicaid, Children's Health Insurance Program (CHIP), or other state-sponsored programs.

To a layperson, repair of a craniofacial anomaly may seem cosmetic in nature. However, reconstructive surgery is performed to treat structures of the body affected aesthetically or functionally by congenital anomalies or birth defects. It is generally done to improve function and ability but may also be performed to achieve a more

typical appearance of the affected structure. The *Ensuring Lasting Smiles Act* excludes coverage for cosmetic procedures.

We'd like to share how access to these procedures impacts the lives of our patients. For example, Peter is an electric guitar player and motivational speaker. Born with Goldenhar Syndrome, he has undergone 30 surgeries in 18 years. All of Peter's surgeries have been to improve his ability to breathe, eat, hear, and see. His largest reconstructive surgery involved placing a custom TMJ implant on his left side, grafting bone from his skull on the right side, and moving both mandibles forward to enlarge his upper airway. The reconstruction also necessitated a second round of orthodontia treatment. Even with private insurance, Peter's out of pocket expenses exceed $100,000 due to high deductibles and copays, no dental coverage, and non-covered needs such as glasses, hearing aids, and prosthetics. Peter is missing his left ear and cannot wear contacts due to cysts in his eyes. An ear prosthesis, therefore, is needed to retain his glasses. Peter would like to have genioplasty (or chin augmentation) to complete his jaw reconstruction, but the surgery is considered cosmetic and not covered. For patients born with congenital craniofacial birth defects, this surgery is most certainly not cosmetic.

Another example is Lauren. Lauren was born with a bilateral cleft lip and palate, which means she had splits on both sides of her upper lip leading up to the base of her nose and was lacking a roof in her mouth. By the time she was seven years old, she had seven surgeries. Her insurance company told her family these surgeries were cosmetic and would only cover some, if any, of the costs. At age 17, Lauren had another major surgery, which consisted of surgically repositioning her upper and lower jaws and chin to correct a severe underbite and adding support in the upper parts of her face, including her cheek area, which she congenitally lacked. Her health insurer initially deemed the surgery unnecessary and notified her that she would have to pay for it herself. Her surgeon pushed back against this denial, explaining that if Lauren did not receive this care, her speech would be significantly impacted – something she had worked so hard to correct following her previous surgeries. Lauren's surgeon also told the insurance company that her face would slowly concave in, growing in a "c" shape, and that her underbite would get progressively worse making it harder for her to eat. The insurer ultimately agreed to cover the cost of surgery; however, they subsequently denied coverage for a dental-related procedure associated with her condition. Her family has spent $20,000 to cover the cost of her treatment since birth.

The *Ensuring Lasting Smiles Act* is supported by the American Society of Plastic Surgeons as well as more than 35 patient and provider organizations

including the American Academy of Pediatrics, American Association of Oral and Maxillofacial Surgeons, American College of Surgeons, American Dental Association, March of Dimes, National Foundation for Ectodermal Dysplasias, National Organization for Rare Disorders, and children's hospitals including the Ann & Robert H. Lurie Children's Hospital of Chicago and the Children's Hospital of Wisconsin.

This bipartisan legislation will have a direct impact on patients with congenital anomalies by providing coverage for medically necessary services that repair or restore a patient's anomaly – ensuring patients with birth defects have access to lifesaving treatments. We look forward to working with you to advance this important legislation.

[Questions submitted for the record and their responses follow:]

MAJORITY MEMBERS:

ROBERT C. "BOBBY" SCOTT, VIRGINIA,
Chairman

SUSAN A. DAVIS, CALIFORNIA
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February 25, 2020

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Ms. Joia Crear Perry, MD
President
National Birth Equity Collaborative
1301 Connecticut Avenue, NW, Ste 200
Washington, DC 20026

Dear Dr. Perry:

I would like to thank you for testifying at the January 28th Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee hearing entitled *"Expecting More: Addressing America's Maternal and Infant Health Crisis."*

Please find enclosed additional questions submitted by Committee members following the hearing. Please provide a written response no later than Tuesday, March 10, 2020 for inclusion in the official hearing record. Your responses should be sent to Ali Hard of the Committee staff. She can be contacted at 202-225-3725 should you have any questions.

I appreciate your time and continued contribution to the work of the Committee.

Sincerely,

ROBERT C. "BOBBY" SCOTT
Chairman

Enclosure

Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee Hearing
"Expecting More: Addressing America's Maternal and Infant Health Crisis."
Tuesday, January 28, 2020 10:15 a.m.

Representative Kim Schrier (D-WA)

- You mention in your testimony that data shows this investment in Medicaid Expansion, such as in your own state of Louisiana, saves money and lives. Can you speak to some of the ways you have seen Medicaid Expansion play a role in positive health outcomes for mothers and their new children? How might extending Medicaid benefits to one year help?
- You noted in your testimony that research indicates women in rural communities are more likely to face maternal mortality. As a representative for a district with many rural areas, this is a concern for me. Washington State has been investing in telemedicine, and has incentives for residents and graduate medical students to re-locate to rural areas. Even with that, however, women in rural areas are at higher risk. Would you speak to some of the ways you can see the provider community working to alleviate this problem? Is there a role for non-physician providers? Are there programs to help rural women with high risk pregnancies live closer to medical care in the later part of pregnancy?

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JEFFERSON VAN DREW, NEW JERSEY

February 25, 2020

Ms. Nikia Sankofa
Executive Director
United States Breastfeeding Committee
4044 N Lincoln Avenue, #288
Chicago, IL 60618

Dear Ms. Sankofa:

I would like to thank you for testifying at the January 28th Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee hearing entitled *"Expecting More: Addressing America's Maternal and Infant Health Crisis."*

Please find enclosed additional questions submitted by Committee members following the hearing. Please provide a written response no later than Tuesday, March 10, 2020 for inclusion in the official hearing record. Your responses should be sent to Ali Hard of the Committee staff. She can be contacted at 202-225-3725 should you have any questions.

I appreciate your time and continued contribution to the work of the Committee.

Sincerely,

ROBERT C. "BOBBY" SCOTT
Chairman

Enclosure

Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee Hearing
"Expecting More: Addressing America's Maternal and Infant Health Crisis."
Tuesday, January 28, 2020 10:15 a.m.

Representative Kim Schrier (D-WA)

- WIC is very near and dear to my heart. In fact, I am working with some of my colleagues to improve provisions for the program. In your testimony, you mentioned WIC in conjunction with both breastfeeding counselor programs and "Baby-Friendly" designated hospitals. Based on your experience, what are the improvements you would like to see in the WIC program?
- In your testimony, you mention that part of the issue with breastfeeding and maternal outcomes is that providers receive limited training in lactation management. In your experience, what are some of the best tactics or practices you've seen to engage the provider community on these issues? How does WIC play a role?

Representative Lauren Underwood (D-IL)

- We are failing to make women's health a priority in this nation. That's why I am proud to be a leader on the PUMP for Nursing Mothers Act, a bill that fixes a legal glitch that currently prevents millions of middle-class moms from reentering the workforce after giving birth. How would enacting my legislation benefit moms, babies, and employers?

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February 25, 2020

Ms. Stacey D. Stewart
President and CEO
March of Dimes
1550 Crystal Drive, Suite 1300
Arlington, VA 22202

Dear Ms. Stewart:

I would like to thank you for testifying at the January 28th Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee hearing entitled *"Expecting More: Addressing America's Maternal and Infant Health Crisis."*

Please find enclosed additional questions submitted by Committee members following the hearing. Please provide a written response no later than Tuesday, March 26, 2020 for inclusion in the official hearing record. Your responses should be sent to Ali Hard of the Committee staff. She can be contacted at 202-225-3725 should you have any questions.

I appreciate your time and continued contribution to the work of the Committee.

Sincerely,

ROBERT C. "BOBBY" SCOTT
Chairman

Enclosure

Health, Employment, Labor and Pensions and Workforce Protections Joint Subcommittee Hearing
"Expecting More: Addressing America's Maternal and Infant Health Crisis."
Tuesday, January 28, 2020 10:15 a.m.

Representative Kim Schrier (D-WA)

- In your testimony, you mentioned how guaranteeing that health plans cover 10 categories of essential health benefits (EHBs) is also critical for moms and babies. Would you speak to the gaps that exist in maternal health and the best ways to alleviate these issues?

- Too many maternal deaths happen in the hospital. Are the same racial discrepancies seen there? Are there any hospitals that have addressed and eliminated these disparities? How? Can this be rolled out nationally?

[Dr. Crear-Perry responses to questions submitted for the record follow:]

Representative Kim Schrier (D-WA)

• You mention in your testimony that data shows this investment in Medicaid Expansion, such as in your own state of Louisiana, saves money and lives. **Can you speak to some of the ways you have seen Medicaid Expansion play a role in positive health outcomes for mothers and their new children? How might extending Medicaid benefits to one-year help?**

Medicaid Expansion has positively impacted the health outcomes for mothers and their new children by lifting the standard of care and increasing rural reimbursements. One way is that Medicaid expansion challenged the coverage pregnant women received through regular Medicaid. Prior to the expansion women only received coverage for prenatal care, delivery, postpartum care, and family planning (Centers for American Progress, 2019). Expanded Medicaid includes coverage that would benefit the essential health of women, which encompasses mental health, chronic diseases management, pediatric services, and more (Centers for American Progress, 2019). Support through the mentioned services benefit the mother and baby both prenatally and postnatally. Other benefits such as breastfeeding support and various screenings are also covered (Centers for American Progress, 2019).

Another positive impact is it helped to improve the finances of rural hospitals (Lewis, Paxton, & Zephyrin, 2019). As a result, those states that participated have experienced lower rates of hospital and/or obstetric unit closures than those states that opted out of the expansion (Centers for American Progress, 2019). States with the expansion had a slower contribution rate to the increase of maternity care deserts (March of Dimes, 2018). Hospital and obstetric unit closures reinforced the barrier to accessing care--i.e. longer travel to receive care--many women in rural communities face. Due to the concern women have for going into labor hours away from a hospital, they are more likely to select to have an early delivery through induction and c-sections (Lewis, Paxton, & Zephyrin, 2019). For pregnant persons in rural areas the expansion and low rates of closures do not increase early elective deliveries, which are procedures that increase risk of complications.

A lack of access to maternal healthcare providers is related to adverse maternal health outcomes—preterm births, low birth weight, maternal mortality, severe maternal morbidity, and postpartum depression (Centers for Medicare & Medicaid Services [CMS], 2019). The Centers for Medicare & Medicaid Services (2019) stated that "38% of all women in the United States don't seek health related services due to cost". Higher rates of low-income mothers received full Medicaid coverage as a result of the expansion, ultimately decreasing the rate of uninsured individuals (Centers for American Progress, 2019). According to the American Journal of Public Health there has been a decline in infant mortality rates for states that have expanded Medicaid (Centers for American Progress, 2019).

While Medicaid expansion has resulted in positive outcomes for both mothers and their new children, there is still opportunity to provide greater support in improving maternal and infant health. Medicaid covers 43% of all births in the United States, meaning at least 43% of birthing persons will need government assistance to receive postpartum care (Martin & Belluz, 2019). Extending Medicaid benefits for new mothers from 60 days postpartum to at least a year will help tremendously. There are ongoing pregnancy-related risks and chronic conditions that women experience up to a year after giving birth, leaving women whose coverage ends two months postpartum vulnerable. One-third of maternal mortality occurs during this postpartum period (Lewis, Paxton, & Zephyrin, 2019). Some of the health concerns that may arise during this period

are hemorrhage, postpartum stroke, postpartum depression and anxiety, and seizures. All of which will impact the health of the baby due to the interconnectedness of the mother's and infant's health.

Access to extended Medicaid benefits in the postpartum period will lessen the burden for women to seek help if they experience complications postnatally. About two-thirds of maternal deaths are preventable; therefore, the option of receiving medical attention could identify problems with easy solutions (Centers for American Progress, 2019). Loss of coverage is a huge issue that negatively affects maternal and infant health in the postpartum period (Centers for American Progress, 2019). It deters women from seeking the help they need from a healthcare professional due to related costs. There have been cases where new mothers received treatment for pregnancy-related issues and once the Medicaid period expired, they loss access to healthcare and prescription assistance, which resulted in adverse consequences. In 2016, Brittney Henry, a Texas mom, died five months postpartum after she could no longer afford her medication following a pregnancy related heart attack (Martin & Belluz, 2019). Had her pregnancy Medicaid benefits been extended, there is a strong possibility that Ms. Henry would be alive today and thriving with her children.

• You noted in your testimony that research indicates women in rural communities are more likely to face maternal mortality. As a representative for a district with many rural areas, this is a concern for me. Washington State has been investing in telemedicine, and has incentives for residents and graduate medical students to re-locate to rural areas. Even with that, however, women in rural areas are at higher risk. **Would you speak to some of the ways you can see the provider community working to alleviate this problem? Is there a role for non-physician providers? Are there programs to help rural women with high risk pregnancies live closer to medical care in the later part of pregnancy?**

The March of Dimes has a report on maternity care deserts that detail hardship for birthing people in rural areas (2018). The provider community can work in various ways to alleviate the problem. Providers can dissolve silos between areas of specialization and between medical/non-medical providers. In order to address the problem of maternal mortality in rural areas there must be an interdisciplinary collaboration between all providers who serve that population. The Camden Coalition of Healthcare Providers, an organization in Camden, NJ composed of multidisciplinary teams to address health issues for those in urban and rural underserved communities, is an example of collaborative efforts that can take place in order to tackle the health risks faced by pregnant women in rural communities. The collaborations can serve as an outlet for providers to work to coordinate regional perinatal services (The American College of Obstetrics and Gynecologists [ACOG], 2014).

Provider communities that serve rural areas can also work to create partnership with those who are not providers. They can work to create relationships with programs like the National Health Service Corps (NHSC) to increase the number of maternal health healthcare providers to serve rural areas. Partnership can also be created between providers and large employers of residents in rural areas to directly reach employees, like the Kearny County Hospital did in Kansas. That relationship between the employers and the Kearny County Hospital resulted in a decline in the number of babies born large for gestational age and increased breastfeeding rates (CMS, 2019). In addition to employers, providers can work to form relationships with the served communities. Following the example of the Rural Maternity and Obstetrics Management Strategies programs, which connects various organizations, FQHCs, hospitals, and programs to increase coordinated care and telehealth, providers

and communities can work together in a network to improve maternal health access and outcomes (CMS, 2019).

As it specifically pertains to healthcare providers, they can implement tools/strategies and trainings to improve the quality of care provided and the workforce capacity. Tools and strategies that can be utilized are the Perinatal Regionalization of Care, the Hub-and-Spoke model, and the Alliance for Innovation on Maternal Health (AIM) safety bundles. Perinatal Regionalization of Care is a strategy that ensures timely access to care appropriate to risk level is provided to all pregnant women (CMS, 2019). The Hub-and-Spokes model is "a model which arranges service delivery assets into a network consisting of an anchor establishment (hub) which offers a full array of services, complemented by secondary establishments (spokes) which offer more limited service arrays, routing patients needing more intensive services to the hub for treatment" (CMS, 2019). AIM safety bundles are evidence-based bundles on how to provide the best care for optimal maternal health. Bundles provided through AIM are aimed at specific problems faced by the maternal population and associated to maternal mortality and severe maternal morbidity.

An expansion in recruitment, certification, and training services for providers (healthcare and non-healthcare) will aid in increasing the workforce capacity in rural areas (Centers for American Progress, 2019). Training can be conducted to leverage the existing workforce. Nurses can be trained to counsel and inform women about postpartum health risks and warning signs (CMS, 2019). Virtual trainings can also be administered to help build the capacity of providers. For example, in some areas family physicians are the only providers of obstetric care (ACOG, 2014). This is a way to provide those family physicians with a level of support to continue their work.

Providers can implement measures to see if the women they serve have any risk factors associated with pregnancy. Screening women is one way to measure if a woman and/or baby are at high-risk for adverse birth outcomes. This will enable providers to create a perinatal care plan to minimize the risk of inauspicious outcomes. Florida has implemented a screening program for pregnant women, which has led to a decrease in infant mortality rates between 1991 and 2015, 8.9 to 6.2 per 1000 live births, respectively (Centers for American Progress, 2019). An important measure that providers can implement on an individual level is how they interact with and care for the women they serve. One aspect of quality of care centers around respect for the patient; providers must acknowledge and take into consideration the expertise of the patients as it concerns their body and experiences (Centers for American Progress, 2019).

NBEC is learning from other experience measures to create a refined and scalable tool that will help health systems quantify patient experiences of respectful care and/or discrimination. These Respectful Maternity Care tools are being produced with the support of the Robert Wood Johnson Foundation and partners. As the scope of policy and practice advancess, a more encompassing response can be achieved. Patient respect coupled with the tools, strategies, and/or trainings will help providers decrease maternal mortality in rural communities.

Collective efforts must be emphasized to fully tackle the maternal health problems in rural communities. There is absolutely space for non-physician providers in the fight to reduce the chances of women in rural communities to experience maternal mortality or other adverse outcomes. Women's health should not be siloed, it should be a comprehensive endeavor throughout the lifespan. A holistic approach must be taken concerning maternal health in rural areas; therefore, a multidisciplinary maternal health workforce should be established. An example of holistic maternity

care is detailed in this report authored through collaboration with Black Mamas Matter Alliance (Muse, 2018).

Countless factors, aside from gynecological and obstetric health, contribute to maternal health, such as social determinants of health (SDoH) and behavioral health. Non-physician providers, like social workers, can address those problems related to mental health, substance abuse, violence, et cetera (CMS, 2019). These providers can connect the women to financial services and nutrition support to minimize the impact of external factors on health. Doulas play an important role in supporting women during the perinatal period. They serve as a bridge between social/emotional and medical support. As it pertains to non-physician medical providers during the perinatal period, midwives and nurses are important to reaching women in rural communities when physicians cannot. Midwives are important because they attend about one-third of deliveries in rural hospitals (CMS, 2019). According to the Centers for Medicare & Medicaid Services (2019), infant and maternal outcomes have improved when midwives are incorporated into the health care system. Also, it is noted that states with expanded midwifery and nursing duties have fewer adverse birth outcomes (Lewis, Paxton, & Zephyrin, 2019).

Programs that move high-risk women who live in maternity care deserts closer to medical care would be an amazing layer to a multidisciplinary maternal care workforce and quality of care improvement. Although the idea would help impact maternal health, there are not many available options. Currently there are not many programs that help women with high-risk pregnancies living in rural areas to move closer to medical care. However, one example is the Regional Maternal & Child Health Program through The University of Texas Medical Branch at Galveston. The primary aim of the program is to connect women in underserved communities to necessary medical resources with a focus on eliminating access barriers. An important aspect of the program is it supplies living accommodations that are closer to their regional center for women with high-risk pregnancies who reside in distant locations (ACOG, 2014). Information on the program was limited. If you would like, we can perform more research and provide that information at a later date.

SOURCES

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[Ms. Sankofa responses to questions submitted for the record follow:]

"Expecting More: Addressing America's Maternal and Infant Health Crisis" Hearing Follow Up Questions

WIC is very near and dear to my heart. In fact, I am working with some of my colleagues to improve provisions for the program. In your testimony, you mentioned WIC in conjunction with both breastfeeding counselor programs and "Baby-Friendly" designated hospitals. Based on your experience, what are the improvements you would like to see in the WIC program?

WIC is one of the nation's leading breastfeeding promotion programs, and its strong collaboration with Baby Friendly USA has helped support birthing hospitals and facilities that adopt the *Ten Steps to Successful Breastfeeding*. WIC agencies collaborate with state and local coalitions to increase the number of Baby-Friendly designated hospitals, offer assistance to local hospitals with lactation training for staff, and strengthen referral networks with hospitals to coordinate post-discharge lactation support for new mothers.

WIC's highly successful Breastfeeding Peer Counselor Program is a critical resource for WIC mothers, providing culturally competent peer-to-peer support. The Peer Counselor Program has a demonstrated record in improving breastfeeding outcomes, including initiation, duration, and exclusivity.[i] As Congress considers opportunities to strengthen the WIC program, continued support and expansion of the Breastfeeding Peer Counselor Program is an important step. Peer counselors are trusted and valued supporters of WIC mothers throughout the breastfeeding journey, and increased investment will ensure that the program has sufficient capacity to meet the needs of all WIC mothers, including through partnerships with Baby-Friendly designated hospitals and home visiting programs.

Additional legislation provides various provisions that would strengthen WIC access and service delivery. Many major program improvements are included in the Wise Investment in our Children (WIC) Act. This legislation resolves significant coverage gaps and streamlines clinic processes to ensure continued access for eligible children. The WIC Act's extension of postpartum eligibility to two years would address nutrition gaps, both improving micronutrient intake (such as folate and iron) while also addressing chronic diet-related conditions such as obesity and diabetes. This extension will not only improve the overall health of mothers, but better prepare women for successful subsequent pregnancies.

The CARE for Families Act, introduced in the House in June 2019, also would provide crucial investments to local WIC agencies to enhance referral networks with healthcare providers to ensure access to both WIC and ongoing healthcare services. Many pregnant women are not connected with WIC services, and the CARE for Families Act wisely invests at the community level to address these coverage gaps and ensure consistent public health messaging from both WIC agencies and healthcare providers. The CARE for Families Act would also invest in community health coalitions and partnerships, including those with

birthing hospitals. Strengthening these partnerships is an important step toward connecting moms with WIC services and improving breastfeeding rates.

In your testimony, you mention that part of the issue with breastfeeding and maternal outcomes is that providers receive limited training in lactation management. In your experience, what are some of the best tactics or practices you've seen to engage the provider community on these issues? How does WIC play a role?

The World Health Organization and UNICEF launched the Baby-friendly Hospital Initiative to help facilities providing maternity and newborn services worldwide to implement the *Ten Steps to Successful Breastfeeding*. The *Ten Steps* summarize a package of policies and procedures that facilities providing maternity and newborn services should implement to support breastfeeding.[ii] The *Ten Steps* are endorsed and promoted by major maternal and child health authorities in the United States, including the American Academy College of Obstetricians & Gynecologists, American Academy of Nursing, and Centers for Disease Control and Prevention.[iii] However, only 28% of the nation's births occur in birthing facilities that are Baby-Friendly designated[iv].

Once families return home, many depend on lactation support and counseling to sustain breastfeeding. Most breastfeeding-related issues, if identified and treated early, need not pose a threat to successful continuation. Unfortunately, many people do not have access to the breastfeeding support they need and deserve to make informed decisions and meet their goals. A distressing 60 percent of mothers report that they did not breastfeed for as long as they intended.[v]

Many families turn to health care providers with questions or when issues emerge. However, training in breastfeeding during medical education for physicians and other healthcare providers varies greatly across schools and programs.[vi] Far too often, health care providers receive little to no clinical training in breastfeeding and infant nutrition, impeding their ability to provide accurate and comprehensive breastfeeding support to the families they serve.[vii]

The Physician Engagement and Training focused on Breastfeeding project[viii], funded by a cooperative agreement with the Centers for Disease Control and Prevention and coordinated by the American Academy of Pediatrics, has been designed to engage physicians and stakeholders to (1) increase availability and accessibility of medical provider education and training related to breastfeeding, and (2) improve capacity of medical practitioners to implement evidence-based maternity care practices, and to promote continuity of breastfeeding-related care in their communities. Research has documented that when physicians' and medical trainees choose to breastfeed, they often do not receive the support from their colleagues and institutions that is needed in order meet their breastfeeding goals.[ix] When providers have poor experiences breastfeeding, it negatively impacts their patient counseling. By increasing support for breastfeeding physicians and trainees, the project aims to transform the culture within the medical community to be more supportive of breastfeeding. The USBC is optimistic that these efforts will have a positive and wide-reaching impact on families.

Lactation support providers also play a critical role in helping families in their communities meet their breastfeeding goals.[x] There are many pathways for individuals to gain the knowledge and experience

needed to offer high quality breastfeeding support to families, across the spectrum of support.[xi] WIC breastfeeding peer counselors are an effective and important part of the continuum of care for breastfeeding.

The WIC Breastfeeding Peer Counseling Program connects pregnant and postpartum women with breastfeeding counselors who share the same background, live in the same neighborhoods, and speak the same language.[xii] Peer counselors are often able to provide realistic and practical guidance and support in ways that most health professionals cannot. Research shows an increase in breastfeeding initiation and duration for clients who are supported by the WIC breastfeeding peer counselor program, and that the program is especially effective at increasing breastfeeding rates among African American WIC moms.[xiii] In the event that more advanced clinical expertise is needed, peer counselors can provide referrals to connect families to appropriate support. The National WIC Association notes that WIC's breastfeeding support activities are strongest when lactation-support professionals, peer counselors, and nutrition staff work together to provide a seamless continuum of care for WIC moms.[xiv]

We are failing to make women's health a priority in this nation. That's why I am proud to be a leader on the PUMP for Nursing Mothers Act, a bill that fixes a legal glitch that currently prevents millions of middle-class moms from reentering the workforce after giving birth. How would enacting my legislation benefit moms, babies, and employers?

Supporting breastfeeding workers is a win-win-win for families, employers, and the health of our nation. Breastfeeding is proven to reduce the risk of a range of illnesses and conditions for infants and mothers.[xv] However, while 83 percent of babies receive breast milk at birth, only 25 percent of U.S. infants are still exclusively breastfed at six months of age.[xvi] Furthermore, a distressing 60 percent of mothers report that they did not breastfeed for as long as they intended.[xvii] Obstacles, especially workplace barriers, make it challenging for many parents to fit breastfeeding into their lives.

The U.S. is one of only three countries that does not guarantee paid leave for new mothers.[xviii] Many parents return to work quickly after birth, before a strong breastfeeding relationship is established because they cannot afford to take unpaid leave or because they do not qualify for federal legal protections. More than half of mothers enter or return to the labor force before their children turn one year old,[xix] with as many as one in four women returning within just two weeks of giving birth.[xx] Many of these mothers choose to continue breastfeeding after their return to work, and need to express (or "pump") breast milk on a regular schedule.

The Break Time for Nursing Mothers law (Break Time law), passed in 2010, provides critical protections to ensure that employees have reasonable break time and a safe, private place to pump breast milk.[xxi] A study examining access to workplace accommodations for breastfeeding, as required by the Break Time for Nursing Mothers provision, and its associations with breastfeeding initiation and duration found that women with both adequate break time and a private space to pump were 2.3 times more likely to breastfeed exclusively at six months and 1.5 times more likely to continue breastfeeding exclusively with each passing month compared to women without access to these accommodations.[xxii]

Unfortunately, the placement of the law within the part of the Fair Labor Standards Act (FLSA) that sets overtime resulted in 9 million women — nearly one in four women of childbearing age — being excluded from coverage.[xxiii] Without these protections, breastfeeding employees face serious health consequences, including the risk of painful illness and infection, diminished milk supply, or inability to continue breastfeeding.[xxiv]

The good news is that employment is compatible with breastfeeding. Businesses of all sizes and in every industry have found simple, cost-effective ways to balance the needs of their breastfeeding employees and their business.[xxv] Studies show that supporting nursing mothers leads to lower employer health care costs, absenteeism, and turnover, as well as improved morale, job satisfaction, and productivity.[xxvi] By putting forth uniform requirements for all employees, the Providing Urgent Maternal Protections (PUMP) for Nursing Mothers Act will create clarity for employers and employees and ensure that all employers can reap the benefits of workplace support for breastfeeding.

The PUMP for Nursing Mothers Act also addresses another consequence of the 2010 Break Time law's placement in the FLSA: that an employee who is denied break time and space has no effective remedy for the violation. By ensuring that women who are denied the ability to pump have a meaningful way to enforce their rights, the PUMP for Nursing Mothers Act will discourage employers from violating the law. Accommodating breastfeeding workers will become the new normal.

The PUMP for Nursing Mothers Act is a critical and common-sense step toward eliminating the barriers to breastfeeding and ensuring all families have the opportunity to reach their personal breastfeeding goals.

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[Ms. Stewart responses to questions submitted for the record follow:]

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March 9, 2020

The Honorable Robert C. Scott
Chairman
Committee on Education and Labor
US House of Representatives
2176 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Scott,

Thank you for the opportunity to testify at the January 28 hearing, "Expecting More: Addressing America's Maternal and Infant Health Crisis." March of Dimes is grateful to the Committee for spotlighting the nation's ongoing health crisis facing moms and babies, and it was an honor to participate in the conversation.

Enclosed you will find responses to questions submitted for the record. If you need further information, please contact Rebecca Abbott, Deputy Director of Federal Affairs for Public Health (rabbott@marchofdimes.org or 202.292.2750).

Sincerely,

Stacey D. Stewart
President and CEO

RESPONSES TO QUESTIONS FOR THE RECORD

In your testimony, you mentioned how guaranteeing that health plans cover 10 categories of essential health benefits (EHBs) is also critical for moms and babies. Would you speak to the gaps that exist in maternal health and the best ways to alleviate these issues?

EHBs have been critical to ensuring women can access health care services before, during and after pregnancy, including coverage for maternity care. Prior to the Affordable Care Act (ACA), only 13 percent of plans in the individual market offered maternity care, and only 11 states had mandates requiring individual plans to cover maternity benefits.[i] Now women purchasing insurance in the individual and small group market can buy health plans that cover maternity care and many other benefits important to maternal health, including mental health and substance use disorder services, prescription drugs, laboratory services, and well-woman preventive care.

The ACA also includes protections to promote the affordability of insurance coverage. It prohibits gender rating and annual or lifetime caps. These provisions ensure that being a women is no longer a preexisting condition and that a complicated pregnancy or early birth will not bankrupt a family.

The ACA's coverage and consumer protection provisions are critical to ensuring women covered by private insurance can access appropriate care before, during and after pregnancy. For women covered by Medicaid, critical coverage gaps exist that threaten the health of mothers. For women across the country, Medicaid's pregnancy coverage ends 60 days after a mother gives birth, leaving moms without insurance during a particularly vulnerable time. Nearly 12 percent of pregnancy-related deaths—not counting those caused by suicide or overdose—occur 43 to 365 days postpartum.[ii,iii] Some states' analyses of pregnancy-associated deaths, which include behavioral health-related causes, find that 50 percent or more of deaths occur beyond the 60-day period.[iv]

March of Dimes strongly supports extending comprehensive Medicaid coverage for all eligible women for a year after birth. Extending postpartum coverage provides an automatic coverage pathway during this vulnerable time, providing coverage for women without other options, mitigating barriers to other coverage pathways, and preventing disruptions in care.

Too many maternal deaths happen in the hospital. Are the same racial discrepancies seen there? Are there any hospitals that have addressed and eliminated these disparities? How? Can this be rolled out nationally?

According to the latest data from the Centers for Disease Control and Prevention (CDC), approximately 17 percent of maternal deaths happen on the day of delivery and another 19 percent occur one to six days postpartum.[v] Black women were more likely to die than white women in these two times periods, though the timing of deaths did not significantly differ

between the two groups.[vi] Apart from maternal deaths, the literature shows disparities exist in the care women receive during labor and delivery, including racial and ethnic disparities in frequency of labor induction, episiotomy, and cesarean birth.[vii] Further, recent research shows 21 percent of Black women giving birth are exposed to racist language or behavior during labor.[viii]

Differential care and disparities in outcomes by race and ethnicity are structural and ingrained. Even as states such as California have taken major strides in reducing maternal mortality rates, Black moms are still dying at higher rates than their white peers.[ix] However, we can take steps to improve maternal health outcomes for women of color. March of Dimes strongly supports implicit bias training for maternity care providers and other medical staff caring for pregnant women. Training helps health care providers and staff recognize bias and change their behaviors to create and sustain a culture of equity within health care institutions. Implicit bias training should be part of a broader health equity strategy that institutions implement to address implicit bias in their systems and improve health outcomes for moms and babies. March of Dimes is proud to be developing our own implicit bias training program to fill an unmet need as states around the country begin to incentivize or mandate such training.

March of Dimes is also a strong supporter of the Alliance for Innovation on Maternal Health (AIM) program, which is funded through the Title V Maternal and Child Health Block Grant. The AIM program is a voluntary maternal safety and quality improvement initiative that has achieved measurable results in preventing maternal mortality and morbidity for patients treated at participating health care facilities. In 2018, AIM released a new bundle called "Reduction of Peripartum Racial/Ethnic Disparities." The new bundle seeks to help health care facilities implement system changes to improve outcomes for mothers of color. This new effort is promising, and March of Dimes looks forward to reviewing preliminary outcomes data when they are available.

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[Whereupon, at 1:02 p.m., the subcommittees were adjourned.]

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