GOAL 2

WHITE HOUSE BLUEPRINT EVIDENCE TO ACTION BRIEFS

Ensure Those Giving Birth are Heard and are Decisionmakers in Accountable Systems of Care

Maternal Health
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THE WHITE HOUSE BLUEPRINT FOR ADDRESSING THE MATERNAL HEALTH CRISIS

The White House Blueprint for Addressing the Maternal Health Crisis (White House Blueprint) has identified goals and actions to reduce the rates of maternal mortality and morbidity, eliminate disparities in maternal health outcomes, and improve the experience of pregnancy, birth, and the postpartum period for people across the United States.

The following Evidence to Action Brief highlights Goal 2 of the White House Blueprint.

Maternal Health Goal 2

Ensure those giving birth are heard and are decisionmakers in accountable systems of care.

CONTRIBUTION TO QUALITY OF LIFE

The White House Blueprint[1] is a "whole-of-government approach to combating maternal mortality and morbidity" so that all people in the United States who are capable of becoming pregnant and giving birth are healthy and safe.

Learning the priorities of pregnant and postpartum people and understanding health care system needs for structural competency are critical for strengthening access to respectful, equitable, and supportive care. Being informed about diagnoses, engaging in shared decision-making, and being supported throughout the reproductive health journey is necessary for health. It is paramount that health care providers, hospital and birthing center administrators, community-based organizations, and other critical stakeholders develop and implement respectful care policies together to eliminate disparities in US maternal health.

BASIC FACTS

In 2021, over 1,200 pregnancy-related deaths occurred in this country, an increase from 861 in 2020.[2] In addition, every year in the US, tens of thousands of near-death severe maternal health complications occur, the vast majority of which can be prevented. Maternal mortality, severe maternal morbidity, and other suffering are the result of inequitable and unjust health care systems. There is immense opportunity to measure outcomes and processes for health care system accountability. Through an ongoing "Cycle Toward Respectful Care,"[3] resources can be directed to health care services that are working well and to address opportunities.

Respectful maternity care is a global and national priority, which calls attention to the need to support dignity, autonomy, and companionship in pregnancy, birth, and postpartum care.[1] The World Health Organization further calls for a resourced and flexible maternity health care system, which necessitates health care team member staffing, training, and ongoing support.[4] The goal is for people to be safe and well through reproductive care. Clinicians, researchers, and birthing people are increasingly defining their needs for positive maternity experiences and offering insights for operationalizing strategies.[5]

The White House Blueprint highlights two efforts aligned with Goal 2 that enhance accountability and ensure that those giving birth are heard and are decision-makers in their health. Perinatal Quality Collaboratives (PQCs) are networks of perinatal health care providers that include hospitals, clinicians, and public health professionals working to improve pregnancy outcomes through quality improvement initiatives and use of best available evidence-based strategies. The Alliance for Innovation on Maternal Health (AIM) is an initiative from the American College of Obstetrics and Gynecology that provides implementation tools and data support for the integration of evidence-based patient safety bundles.[1] Many AIM patient safety bundles originated (through refinement and testing) within state PQCs. AIM released a Postpartum Discharge Transition change package in May 2023 which sets new standards for patient-focused care, including assessing birthing people's experiences of care and incorporating those results in quality metrics dashboards.[6] Critically, partnerships with patients and family members to improve systems of care is recommended to be funded. Another highlight of the standards is the recommendation for data to be disaggregated, at least by patient race and ethnicity. When implemented fully, PQCs and AIM initiatives have improved maternal health outcomes [1]; however, they are yet to be fully scaled and consistently implemented.

The White House Blueprint also asserts that addressing biases and stereotypes is a critical part of improving quality of care for all pregnant people and must be embedded within efforts to enhance accountability to those being served. Black individuals and other birthing people of color regularly report that their concerns are dismissed in health care settings.[1] Increased understanding of and attention to the biases that maternal health care providers bring to their daily practice are essential, as are enhanced transparency and accountability when there are poor maternal health outcomes. The White House Blueprint commits to improving maternal and infant health outcomes by ensuring that those giving birth are heard and are decision-makers in accountable systems of care. To this end, the White House Blueprint commits to the following actions:

Action 2.1. **Explore opportunities to advance equitable, high-quality maternity care** provided by hospitals, including engaging with the public on possible revisions to the Conditions of Participation for hospitals receiving funding from the Medicare and Medicaid programs, as well as proposing a new "Birthing-Friendly" hospital designation to publicly report those facilities with a demonstrated commitment to maternal health through participation in perinatal quality improvement programs and implementation of evidence-based practices.

Action 2.2. **Bolster the voice of communities of color when analyzing factors contributing to pregnancy-related deaths** by developing a roadmap to increase community participation in state maternal mortality review committees (MMRCs) and incorporating community participation in future funding opportunities when allowable.

Action 2.3. **Empower [American Indian/Alaska Native] AI/AN pregnant and postpartum women and educate providers** by expanding the Hear Her™ campaign to include culturally relevant materials to raise awareness of urgent maternal warning signs and improve communication between patients and providers.

Action 2.4. **Make insurance coverage and costs of care transparent and easy to understand** by financially protecting consumers from surprise medical bills and providing uninsured and self-pay patients with cost estimates before scheduled care.

Action 2.5. **Empower women with their own data**, enabling more women to get automated access to their electronic prenatal, birth, and postpartum health records.

Action 2.6. **Train providers on implicit biases, culturally and linguistically appropriate care, and behavioral health needs** of pregnant and postpartum women, including screening and referral for abuse and maltreatment.

Action 2.7. **Address systemic discrimination in health care by providing guidance on the prohibition of discrimination** on the basis of race, color, national origin, age, disability, or sex (including pregnancy, sexual orientation, and gender identity), in various health programs and activities.

Action 2.8. **Encourage the removal of structural barriers that prevent women with disabilities** from receiving adequate reproductive care by supporting providers' adoption of the U.S. Access Board's standards for accessible medical diagnostic equipment (MDE), such as exam tables, mammography equipment, and weight scales.

Action 2.9. **Embed equity into Quality Family Planning Guidelines** to provide guidance to help clients prevent or achieve pregnancy, basic infertility services, preconception health services, pregnancy testing and counseling, contraceptive services, and sexually transmitted disease services.

Action 2.10. **Support care coordination by implementing Pregnancy Medical Home demonstration sites** that emphasize quality and care coordination through a team-based approach to care with the goal of reducing adverse maternal health outcomes and maternal death.

Action 2.11. **Support state innovation efforts by establishing state-focused Maternal Health Task Forces** and improving state-level data surveillance on maternal mortality and severe maternal morbidity.

Action 2.12. **Reduce the stigma of postpartum depression** and other behavioral health conditions through a media campaign to raise awareness about postpartum depression.

Action 2.13. **Support breastfeeding (for those who wish to breastfeed) through the Reducing Disparities in Breastfeeding Innovation Challenge**, which will identify effective programs that increase breastfeeding initiation and continuation rates, decrease disparities among breastfeeding individuals, and demonstrate sustainability and the ability to replicate and/or expand the program.

Action 2.14. **Work with Congress to ensure the President's budget proposal on maternal health is fulfilled**, so that states, cities, and counties can improve quality of care and prevent unnecessary deaths by enrolling every state in the Alliance for Innovation on Maternal Health program and facilitating Perinatal Quality Collaboratives operating at full capacity in every state.

HOW ARE WE DOING?

Below we highlight data related to Goal 2. Racial, ethnic, geographic, and socioeconomic disparities emphasize where efforts should focus to improve health outcomes related to the goal.

Table 1: Maternal Mistreatment During Childbirth 2010–2016 in the United States, by Race and Ethnicity (n= 2,138)

Type of Mistreatment	Black n = 320 n (%)	Hispanic n = 188 n (%)	Indigenous n = 64 n (%)	Asian n = 90 n (%)	White n = 1,416 n (%)
Your private or personal information was shared without your consent	2 (0.6)	5 (2.7)	2 (3.1)	-	17 (1.2)
Your physical privacy was violated (e.g., being uncovered or having people in the delivery room without your consent)	27 (8.4)	12 (6.4)	6 (9.4)	7 (7.8)	62 (4.4)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	35 (10.9)	30 (16.0)	10 (15.6)	9 (10.0)	90 (6.4)
HCPs threatened to withhold treatment or to force you to accept treatment you did not want	21 (6.6)	11 (5.9)	7 (10.9)	6 (6.7)	51 (3.6)
Health care providers threatened you in any other way	6 (1.9)	8 (4.3)	3 (4.7)	1 (1.1)	26 (1.8)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	41 (12.8)	23 (12.2)	7 (10.9)	12 (13.3)	79 (5.6)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	6 (1.9)	4 (2.1)	-	1 (1.1)	16 (1.1)
Any mistreatment (one or more of the above)	72 (22.5)	47 (25.0)	21 (32.8)	19 (21.1)	199 (14.1)

Mistreatment of birthing persons is most likely to occur among women of color. In the first study of its kind, researchers found that Indigenous birthing persons were the most likely to report experiencing at least one form of mistreatment (32.8%), followed by Hispanic birthing persons (25.0%) and Black persons (22.5%). Women who identified as White were least likely to report that they experienced any of the mistreatment indicators (14.1%).

Source: Vedam S, et al. The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States. Reprod Health. 2019:16(77).

Table 2: Maternal Mistreatment During Childbirth 2010–2016 in the United States, by Socioeconomic Status (n= 2,138)

Type of Mistreatment	Low SES	
	Yes (n=743) n(%)	No (n=1,395) n(%)
Your private or personal information was shared without your consent	12 (1.6)	14 (1.0)
Your physical privacy was violated (e.g., being uncovered or having people in the delivery room without your consent)	47 (6.3)	70 (5.0)
Health care providers (doctors, midwives, or nurses) shouted at or scolded you	89 (12.0)	93 (6.7)
HCPs threatened to withhold treatment or to force you to accept treatment you did not want	48 (6.5)	49 (3.5)
Health care providers threatened you in any other way	19 (2.6)	25 (1.8)
Health care providers ignored you, refused your request for help, or failed to respond to requests for help in a reasonable amount of time	78 (10.5)	88 (6.3)
You experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)	19 (2.6)	8 (0.6)
Any mistreatment (one or more of the above)	160 (21.5)	209 (15.0)

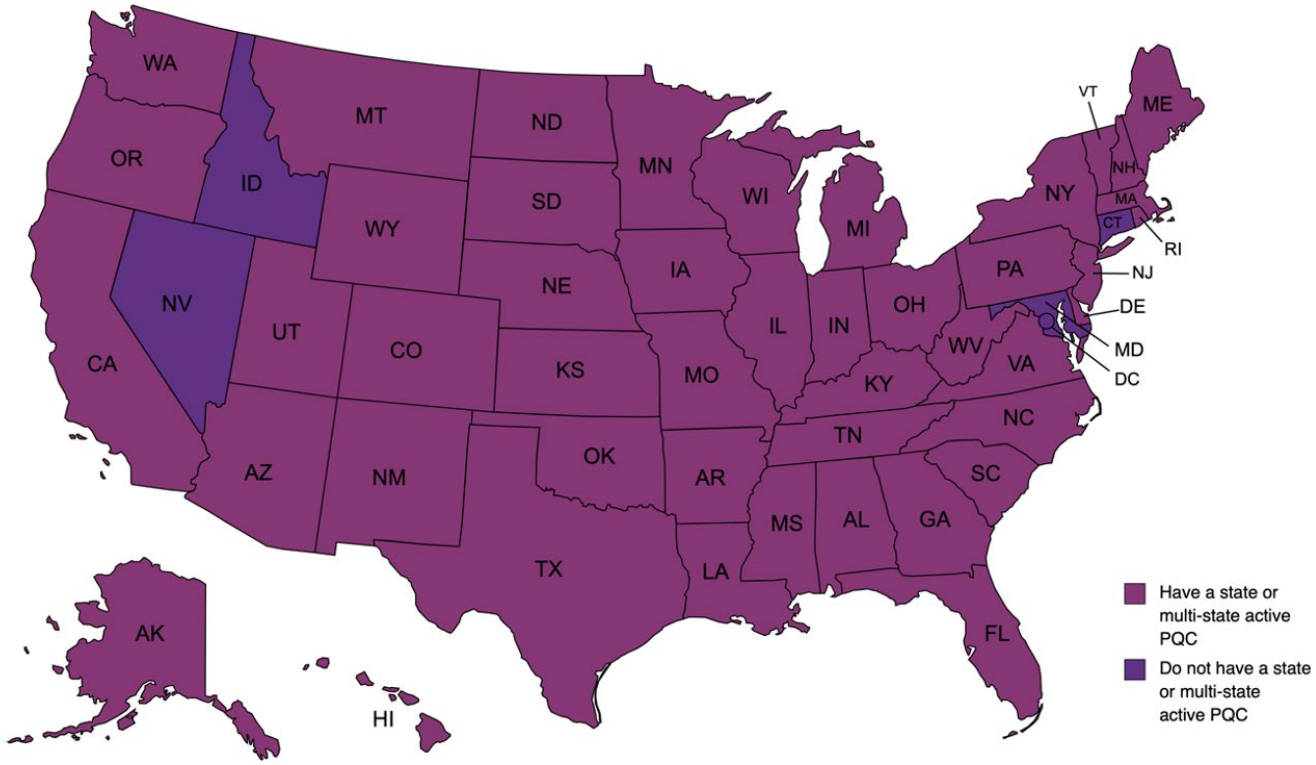
Women who reported low socioeconomic status (SES) were twice as likely to report being threatened or shouted at by health care providers, compared with women with moderate or high SES. At the intersection of race and SES, women of color with low SES had higher rates of mistreatment compared with White birthing persons with low SES (26.9% vs 17.7%, respectively; data not shown).

Source: Vedam S, et al. The Giving Voice to Mothers study: inequity and mistreatment during pregnancy and childbirth in the United States. Reprod Health. 2019:16(77).

CALL TO ACTION

The need to "retrofit, reform, and reimagine" for maternal health equity, as outlined by Dr. Monica McLemore, is urgent.[10] Equitable, respectful care is critical to improving maternal and infant health outcomes. Pregnant women and individuals with reproductive capability must be heard and respected as decision-makers throughout the process of becoming pregnant, birthing, and thriving postpartum.[1] Responsive systems of care can demonstrate the value of patient experiences and partner with health care professionals to support and continually improve holistic health outcomes.

Figure 1: Perinatal Quality Collaboratives in the United States, 2023



Nearly all US states have a state or multi-state active Perinatal Quality Collaborative (PQC). PQCs seek to improve pregnancy outcomes through quality improvement initiatives and using best available evidence-based strategies.

Source: National Institute for Children's Health Quality. National Network of Perinatal Quality Collaboratives, Map. Accessed September 13, 2023

Table 3: Alliance for Innovation on Maternal Health (AIM) Patient Safety Bundles, 2023

Obstetric Hemorrhage
Severe Hypertension in Pregnancy
Safe Reduction of Primary Cesarean Birth
Cardiac Conditions in Obstetric Care
Care for Pregnant and Postpartum People with Substance Use Disorders
Perinatal Mental Health Conditions
Postpartum Discharge Transition
Sepsis in Obstetrical Care

The American College of Obstetricians and Gynecologists has developed AIM patient safety bundles as a structured way of improving the process of care and patient outcomes.. Forty-nine states and the District of Columbia are enrolled in this quality-improvement initiative in at least 1 of the above 8 topic areas.

Source: American College of Obstetricians and Gynecologists. Patient Alliance for Innovation on Maternal Health Patient Safety Bundles. Accessed September 13, 2023.

STORY BEHIND THE DATA: FACTORS AFFECTING PROGRESS

The US system of reproductive health care does not equitably see, hear, or value the voices and experiences of pregnant persons and individuals capable of becoming pregnant. Multilevel systemic barriers to quality maternal health care services exist and contribute to pregnancy-related deaths; they include: individual-level barriers (e.g., lack of access to information on maternal warning signs and when to seek care), interpersonal barriers (e.g., health care provider implicit bias, failure to believe pregnant women, and errors such as misdiagnosis), and systems factors (e.g., systemic racism, lack of interpretation, service utilization, and inadequate care coordination).[5,7] Even when interventions are in place to address these barriers, the health care system often lacks meaningful measures of accountability.[5,7]

As noted above, establishing PQCs and implementing AIM patient safety bundles are recommended evidence-based actions that can help remove some of these barriers. Full-scale adoption of these practices, however, has not happened, for several reasons: First, not all states have been funded to fully implement these initiatives; second, hospitals are not required to adopt these best practices and may lack the resources needed to implement them; and third, incentive structures may not be in place to motivate states and/or hospitals to adopt these actions and hold their providers accountable.[1]

Other barriers to the receipt of respectful care are related to the root cause of health inequities: a hierarchy of human value, which manifests as racism and intersecting biases.[8] Pregnant persons who have a disability, identify as a person of color, or are from a religious minority group are at a greater risk of being mistreated before, during, and after pregnancy.[1] In the first quantitative study to examine mistreatment

during pregnancy and childbirth, 1 in 6 women (17%) experienced some kind of mistreatment during pregnancy and/or childbirth. Disparities by race, ethnicity, socioeconomic status, and geography exist (see Table 1 and Table 2). Identifying as a person of color (Black, Hispanic, Indigenous, or Asian) increased the likelihood of experiencing any type of mistreatment.[9] Identifying as a person of color with low socioeconomic status, nulliparous, and young (17 to 25 years old) also increased the likelihood of mistreatment.[9] In addition, women of color who experienced a medical or social risk factor (e.g., elevated pregnancy risk and social risk) were more likely than White women to report any type of mistreatment during childbirth.[9]

Factors affecting progress related to maternal mistreatment are related to accountability and transparency. Research suggests that a lack of transparency related to statistics on institutional-level quality of care measures, maternal health outcomes, and health care costs can lead to mistreatment during pregnancy and childbirth. Evidence also suggests that there is less accountability in the health care system when mechanisms are not in place for patients and their companions to share their positive and negative experiences.

WHAT COULD BE DONE TO ADDRESS THE ISSUE?

The White House Blueprint identifies actionable steps to address Goal 3. In addition, experts from the maternal and child health field have identified innovative, evidence-informed strategies from several databases and national repositories.

Maternal & Child Health Innovations

MCH experts selected the following resources for action after a review that included: the MCHbest Database, a database developed to aggregate evidence-based strategies that can be used as is or adapted to fit local and state-level contexts; the Association of Maternal & Child Health Program's Innovation Hub (AMCHP), a searchable repository of local and state practices, policies, and community-based innovations considered to be "what's working" in the MCH field; the Robert Wood Johnson Foundation's What Works for Health (RWJ) database, a tool that helps local communities to identify policies and programs that fit within their context and match their priorities; the Maternal Health Learning & Innovation Center, a national resource for improving maternal health inequities; and a search of leading organizations and agencies working in this field.

- Alliance for Innovation on Maternal Health. AIM is a national maternal safety and quality improvement initiative that provides implementation and data support for the adoption of evidence-based patient safety bundles. AIM works through state teams and health systems to align national, state, and hospital-level efforts to improve overall maternal health outcomes, and can provide technical assistance and implementation support for states implementing the safety bundles.
- Culturally and Linguistically Appropriate Services in Maternal Health Care. This open-access training addresses cultural humility, person-centered care, and combating implicit bias across the continuum of maternal health care.
- HEAR HER Campaign. A social media campaign from the CDC, this effort is targeted to multiple races and ethnicities to provide information from people with lived experience to help prevent pregnancy-related deaths by sharing potentially life-saving messages about urgent warning signs.
- It Takes a Village: Giving Our Babies the Best Chance (ITAV). A community education and engagement series, ITAV raises awareness and educates Native Hawaiians/Pacific Islanders in Utah about maternal and infant health in the context of Pacific Islander cultural beliefs and practices. (AMCHP)
- Maternal Experience Survey. The MES is a community tool designed to improve care and reduce childbirth-related disparities for Black pregnant people. Developed by the NAACP Atlantic City Black Infant and Maternal Mortality task force and the Prematurity Prevention Initiative, the tool allows pregnant people to share their experiences in a safe manner embedded with identity acceptance and respect. (AMCHP)
- Maternal Mortality Prevention Program. Colorado's Maternal Mortality Prevention Program uses a three-pronged approach of community-led solutions, clinical quality improvement, and public health programs to eliminate preventable maternal deaths, reduce maternal morbidities, and improve population health and health equity for pregnant and postpartum people in the state. (AMCHP)
- MoMMA's Voices Champions Training Center. The center offers training to patient family partners who desire to be effective

participants in improving maternal health outcomes. (AMCHP)

- Perinatal Quality Collaboratives. PQCs are state or multistate networks of teams working to improve the quality of care of mothers and babies. These collaboratives can improve birth outcomes, reduce bloodstream infections in newborns, and reduce pregnancy complications.
- Postnatal Patient Safety Learning Lab. Located at the University of North Carolina at Chapel Hill, this research team has developed a series of digital stories to build empathy around birthing people's experiences of health care. The open-access animations can be used to increase awareness and promote more patient-focused care.
- Quality Improvement in Maternity Care via Project ECHO. This program in Utah seeks to educate and encourage hospitals statewide to implement components of the evidence-based AIM maternal safety bundles. (AMCHP)
- Respectful Maternity Care Collaborative. The partnership identifies stakeholder priorities to eliminate Black maternal health disparities.
- Respectful Care eModules. The American College of Obstetricians and Gynecologists has developed and offers free online courses to address race and equity in OB-GYN care. Modules cover three topics: race and equity, respectful care, and historical foundations of obstetric racism.
- Storytelling as a Public Health Strategy. Sharing stories of people affected by the maternal health crisis has become a well-documented strategy to push for systemic change. An example is the acclaimed documentary *Aftershock*, released in 2022, which profiles families that suffered loss and then became activists in the birth justice movement.

State Maternal Health Innovations from the Health Resources & Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) Grantees

The State Maternal Health Innovations (MHI) initiative, funded by HRSA's MCHB, currently provides funding to 18 states to develop, implement, and evaluate state-level equity-centered innovations. Below we highlight an innovation that addresses Goal 2 from the MHI cohorts (2019–2024):

- Illinois. Innovations to ImPROve Maternal OuTcomEs in Illinois (I PROMOTE-IL) has a digital project, Illinois Maternal Health Digital Storytelling Project, that centers women's voices and personal perspectives alongside maternal health data in short online videos. More information is here.

Resources from the MCH Evidence Center's Digital Library

The MCH Digital Library is a digital repository of evidence-based and informed resources (toolkits, briefs, whitepapers, etc.) with seminal and historic resources. The following may support Goal 2.

- Centers for Disease Control and Prevention. Perinatal Quality Collaboratives: PQC Webinar Series, 2012–2013. National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health. Atlanta, GA. Last reviewed August 22, 2023. Accessed September 13, 2023.
- MCH Workforce Performance Center. Diversity and Health Equity in the Maternal and Child Health Workforce: A Resource Guide to Key Strategies and Actions for MCH Training Programs. Maternal and Child Health Bureau. 2016. Rockville, MD. Last reviewed February 20, 2015. Accessed September 13, 2023.

Strategy Development Criteria

To select impactful strategies for local implementation, an organization may consider using the following criteria, based on the Results-Based Accountability framework outlined in the book *Trying Hard Is Not Good Enough* by Mark Friedman.

- **Specificity:** Ensure strategies are clearly defined, including responsible parties and timelines.
- **Leverage:** Evaluate how strategies can improve data quality and reliability.
- **Values:** Assess alignment with community and organizational values.
- **Reach:** Consider feasibility and affordability at the required scale.

Visit maternalhealthlearning.org/Blueprint for more details.

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The MHLIC is available for consultation, coaching, and technical assistance to support your implementation of any innovations to improve maternal mortality and morbidity. For more information, visit https://maternalhealthlearning.org/connect.

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