BACKGROUND CONTEXT FOR RECOMMENDATIONS

TO

U.S. SECRETARY OF HEALTH AND HUMAN SERVICES

From

Advisory Committee on Infant Mortality (ACIM)

August 2021

Infant and maternal mortality, along with life expectancy, are the leading international indictors of a nation's health. Each of these indicators shows the United States steadily falling further behind other high-income nations. Compared with other countries who are members of the Organization for Economic Cooperation and Development (OECD), the U.S. ranks number 34 out of 44 countries in infant mortality[i] and has the highest maternal mortality rate.[ii] [iii] For example, per 100,000 live births, 3.2 German women vs. 17.4 US women will die.[iv] Outcomes are far worse for US Black, Indigenous, and People of Color (BIPOC) mothers and infants; 43.5 Black US women die per 100,000 live births.[v] The U.S. life expectancy at birth (an indicator directly affected by the infant mortality rate) ranks 28 out of 44 among OECD countries.[vi] For the overall health of our country, it is long-past time for us to make improving the health of our mothers and babies a national priority.

Over the last two years the Advisory Committee on Infant Mortality (ACIM), the Federal Committee charged with advising the HHS Secretary on Department activities and programs directed at reducing infant and maternal mortality and improving the health status of pregnant women and infants, has been examining the factors contributing to the poor birth outcomes in this country. After reviewing the scientific and practice-based literature and hearing testimony from maternal and child health experts and advocates, healthcare providers, academicians, community-based organizations, and parents, ACIM has developed a set of recommendations on how to protect and improve the health of mothers and babies.

FOCUS ON ELIMINATING PERSISTENT RACIAL DISPARITIES

ACIM recognizes that while the causes of infant and maternal mortality are complex and multifactorial, there is mounting evidence that one of the strongest factors influencing our deplorable rates is long-standing disparities in poor birth outcomes that disproportionally impact individuals from BIPOC communities. Among the more than 21,000 infants who died in the United States in 2018, the infant mortality rate for non-Hispanic Black infants was more than double the rate of deaths in the first year of life for non-Hispanic white infants. An estimated 700 to 900 pregnancy-related deaths occur in the U.S. each year, with Black and American Indian/Alaska Native (AI/AN) women two to five times more likely to die from pregnancy-related causes than white women; this glaring disparity increases with the age of the woman.[vii]

This persistence of racial disparities further erodes our international status. More importantly, preventable infant and maternal deaths deprive our country of the contributions their lives could have made. As the U.S. population becomes more diverse, reducing and eliminating these disparities will have a profound impact on the health outcomes of mothers, infants, and families and the overall health of our country.

STRUCTURAL RACISM IMPACTS MATERNAL AND INFANT HEALTH OUTCOMES

Increasingly evident is that structural and systemic racism in our healthcare system and in our overall society underlies these unacceptable disparities. Well documented studies have shown that Black Americans, Hispanics/Latinos, and Native Americans receive a lower quality of healthcare and are less likely to receive routine medical procedures than whites.[viii] The landmark Institute of Medicine report, '**Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare**', reviewed a national sample of over 100 studies from a ten-year period and found significant and pervasive racial and ethnic healthcare disparities, defined as differences in the quality of healthcare not due to access-related factors or clinical needs, preferences, and appropriateness of intervention.[ix]

More recently, the American Medical Association in its '**2021-2023 Organizational Strategic Plan to Embed Racial Justice and Advance Health Equity'** reinforces and expands on these findings from the last century: "*The disproportionate impact of early death and morbidity on Black, Latinx and Indigenous people is rooted in our country's legacy of powerful systems that structure opportunity and assign value that historically advantages whites and oppresses historically minoritized and marginalized communities, thereby setting the foundation for neighborhood and community level social conditions that exist related to housing and education as an example. This is inextricably intertwined with patients' social needs. This legacy determines the type of health outcomes in mortality and morbidity that people and their communities will experience."*[x]

Specific to pregnant women, a 2021 report **'Reversing the U. S. Maternal Mortality Crisis'** from the Aspen Health Strategies Group[xi] stated that "*Maternity care has been directly affected by racism-based policies … the data show that, even after controlling for age, income, and other risk factors, Black women have higher maternal mortality rates than White women. … This points to the role of present-day racism as a primary cause of maternal mortality."* We also know that racial disparities in food security, education, housing, environmental conditions, economic security, and the criminal legal system that are too prevalent in our country also contribute to disparities in maternal and infant health outcomes.[xiixiii]

PRIOR COVID-19 SPECIFIC RECOMMENDATIONS

The COVID-19 pandemic, which ACIM addressed in its June 29, 2020 recommendations to the HHS Secretary, continues to directly and indirectly affect the health of mothers and babies. The pandemic has highlighted the deficiencies in many of the programs and systems that impact the health of infants, mothers, and women of reproductive age. It also has demonstrated how the shortcomings of those programs and systems have had disproportionate detrimental effects on individuals from BIPOC communities. Most evident are the inadequacies of our healthcare, public health (including environmental health), and social/human service systems, and the data and information technology (IT) systems that support them. Making all these problems more acute and widespread are the longstanding deficiencies and inequities in our housing, economic, education, immigration, transportation, and food systems.

Adequately and effectively addressing all these deficiencies requires a comprehensive and sustained commitment to the health of infants, mothers, and women of reproductive age with priority focus on addressing the inequities in all systems that have led to the disparities in health outcomes. Effectively addressing and recovering from the current COVID-19 pandemic should serve as a starting point for our efforts with the goal of a more widespread transformation of all systems to optimally meet the needs of all mothers and infants.

The set of twelve COVID-19 related recommendations forwarded by ACIM to the HHS Secretary in June 2020 focused on three strategic approaches to improving perinatal and newborn clinical care during the COVID-19 crisis.[xiv]

- Protect Pregnant Women and Infants from Harm and Promote their Well-being,
- Support Innovations in Finance and Policy, and
- Strengthen Data and Surveillance Systems Across Sectors to Monitor Impact

These prior recommendations are still relevant to the health of mothers and babies as the COVID-19 pandemic continues plague our country and the world and should be considered along with ACIM's recommendations accompanying this document.

The last paragraph of that COVID-19 document noted that "… *the COVID-19 pandemic is being compounded by Racism - an acknowledged public health crisis in the United States. … (Systemic racism has been recognized as driving social and environmental determinants of infant and maternal health, accounting for a disproportionate burden of disease and deaths among Black and Indigenous mothers and their infants. … This Advisory Committee plans to address the public health crisis of racism, specific to preventing maternal and infant mortality and eliminating racial disparities and make strategic recommendations for your consideration*."

That focus on racism and its negative impacts on the health of mothers and babies is embedded in the Committee's recommendations being submitted today.

FIVE ISSUES OF SPECIFIC AND URGENT CONCERN

Now is a critical time for mothers and babies in our country. Each day we learn more about the impact of COVID-19, housing and food insecurity, incarceration, substance use, environmental toxics, and immigration issues on the health of mothers and babies. We are also being confronted with evidence of how structural racism and discrimination are exacerbating these issues and perpetuating the unconscionable health disparities we have in this country. ACIM has identified five additional major areas of concern, intensified or made evident by current events, which demand immediate attention if we are to prevent needless deaths of mothers and infants.

I. Care Systems and Financing of Care

Access to high quality maternity care is essential to improving the overall birth outcomes in our country. However, access to maternity care is not uniform throughout the U.S. According to a 2020 report from the March of Dimes (MOD),[xv] there are more than 5.3 million women residing in more than 1,000 counties in the United States without an obstetrician, midwife, or maternity facility. While maternity care deserts are mainly in rural areas due to travel distances to hospitals and health care providers, poor access to maternity care can also occur in urban areas or areas adjacent to urban centers due to barriers to access like transportation, insurance, and culture and language factors. The MOD report notes that there are 125 urban counties that have no obstetricians and no hospitals providing obstetric services. There are an estimated 1.1 million women living in these urban maternity care deserts, with 1 in 8 of these women lacking health insurance.

Improving access to high quality maternity care services for everyone across our country will, at a minimum, require:

- increasing the number of facilities providing the broad range of essential maternity services or maximizing the use of existing facilities, e.g. expanding the use of accredited birth centers and, recognizing that 59% of hospital births occur in hospitals with fewer than 1000 births per year, regionalizing care using established level of care processes (e.g., ACOG, Joint Commission[xvi], CDC LOCATEe[xvii]),
- expanding and diversifying the maternal and child health and perinatal workforce to include to community-based providers such as public health nurses, nurse midwives, social workers, physicians, community health workers, and doulas, and
- increasing insurance coverage for maternity care services from pre-pregnancy to at least one year postpartum through expansion and enhancement of Medicaid and piloting new payment models for maternity care.

Given the fact that poor access to facilities, providers, and insurance is disproportionately experienced by BIPOC, rural, and poor women, requires that all program, service, and policy initiatives address the specific needs of these individuals.

Recognizing the deficiencies in our current healthcare and social/human service systems that leave too many individuals and families uninsured, financially burdened, and perplexed by complex bureaucracies that serve as a barrier to care,[xviii] ACIM recommends that efforts, in addition to the those mentioned above, should be made to reconceptualize how care, especially maternal healthcare, is delivered by supporting community-based maternity care, group prenatal care, and accredited birth centers. This should ideally be done in the context of a comprehensive and sufficiently and equitably financed healthcare and social support system dedicated to assuring the best possible health outcomes for individuals, families, and the communities in which they live.

In the absence of overall system transformation, focused interventions will be required to improve how care is delivered through changes in Medicaid, targeted COVID and ARPA funding, care systems improvements, workforce development, and enhanced data collection efforts. Given that Medicaid pays for over 50% of births in this country, this program plays a significant role in maternity and perinatal care, especially for poor families. With expansion of and improvements in Medicaid, birth outcomes could be markedly improved and disparities in outcomes reduced.[xix] The evidence for such transformation can be seen in the State of California as a Medicaid expansion state and with its Maternal Quality Care Collaborative (MQCC).[xx] Employing a systematic approach with quality improvement initiatives and research, California saw maternal mortality decline by 55 percent between 2006 to 2013 from 16.9 down to 7.3 per 100,000, when the rest of the USA saw an increase to 22.7 per 100,000.

The fee-for-service financing mechanism for prenatal care has not been conducive to improving birth outcomes. It rewards services delivered, not outcomes achieved. It has limited the involvement of non-physician healthcare providers and impeded the development and implementation of alternative service systems and approaches.[xxi] In the absence of overall system transformation and funding for universal access to care, efforts should be made to evaluate other financing mechanisms like bundled payment for maternity care, per member per month payment, maternity medical homes, and accountable care organizations using value-based (outcome-based) performance measures. As part of this will be the necessity for CMS, state Medicaid, and managed care organizations to appropriately compensate for collaborative comprehensive perinatal care, facilitate information sharing between clinical and community providers, and not base outcomes on delivery alone.

One long neglected and underfunded part of our healthcare system is the Indian Health Service (IHS). Given the grievous disparities in birth outcomes for mothers and babies in Indigenous communities, care for this population needs immediate attention. In exchange for the surrender and reduction of ancestral tribal lands and resources, the United States signed 375 treaties which

has shaped the unique trust obligation between the federal government and tribes, creating the largest pre-paid health plan in our history.

The Indian Health Service is obligated to provide health care to members of the 574 federally recognized tribes by means of: (a) direct services operated by IHS; (b) services operated by tribes through contracts or compacts with IHS; (c) services involving contracts and grants to Urban Indian Organizations that provide health care and referral services to Urban Indian Health programs; and (d) services contracted directly between IHS and private sector medical providers that supplement Native American health care services. A 2018 U.S. Commission on Civil Rights Report found the "*efforts of the federal government have been insufficient to meet the promises of providing for the health and wellbeing of tribal citizens, as a vast health disparity exists today between Native Americans and other population groups*."[xxii] Chronic underfunding of IHS has only worsened the disparity. According to the 2019 Tribal Budget Formulation Workgroup, funding IHS at $37.61 billion over the next 12 years, with $9 billion immediately released to IHS for fiscal year 2021-2022, is needed to meet the needs of Native people.[xxiii] The President's Fiscal Year 2022 Budget aims to allocate $8.5 billion to HIS for providing care for 2.56 million AI/AN, which falls short of the Tribal Budget Workgroup recommendation of $12.7 billion.

Care for AI/AN pregnant women and babies remains particularly inadequate. Of the $6.2 billion provided to IHS in the current Fiscal Year 2021 only $5 million of this funding is dedicated to efforts at improving Maternal Health by way of: expanding standardized screening, addressing social determinants of health, increasing cultural awareness, updating IHS standards of care, training providers, increasing targeted outreach to pregnancy women and women of childbearing age at risk for substance abuse disorders, and providing patient outreach and education in addition to supporting IHS and tribal hospitals that provide labor and delivery services.[xxiv] While these services are needed, the $5 million funding dedicated to these efforts to improve maternal health is not commiserate with the magnitude of the existing disparities and the myriad problems faced by Native women and infants. Therefore, it is essential that DHHS advocate for immediate and adequate funding to be dispersed to IHS in hopes of improving AI/AN maternal and infant health.

II. Workforce Development

Acknowledging the limitations of inter-country comparisons, the data from other countries and the United States tend to show that midwifery-led models of care have excellent outcomes, reduce overall costs of care, and meet the needs and preferences of most pregnant and postpartum women who present without high risk conditions.[xxv] [xxvi][xxvii] Studies have also demonstrated the positive impacts of doulas or skilled birth attendants on birth outcomes including: lower cesarean rates, decreased use of perinatal analgesia, increased maternal satisfaction, shorter labors, better five-minute Apgar scores, fewer babies with low birth weight, and increased initiation breastfeeding.[xxviii] Doula support may also be a way to reduce the impacts of racism and racial bias on pregnant and postpartum people of color.[xxix] Race

concordant care has been identified as a factor in potentially reducing health disparities in birth outcomes.[xxx] Doulas are one of the most diverse groups supporting pregnant individuals in our healthcare system. Becoming a doula has been a way for many women of color to enter the health field.[xxxi] However, because of payment issues and bureaucratic barriers, use of doula services remains limited, and they are often available only to higher-income women who can afford to pay for them outside of the insurance system.

III. Environmental Contributions to Infant and Maternal Health and Mortality

While COVID-19 has received most of our attention over the last year, ACIM is increasingly concerned about the accumulating information about the impact of environmental exposures on the health of mothers and infants.[xxxiixxxiii] Pregnant women and infants who are Black, Indigenous, and People of Color are disproportionately impacted by climate change and the cumulative exposures to toxic chemicals and pollution combined with other stressors, including structural racism. In a review of almost 33 million births in the USA there was found to be a significant association between air quality and heat and serious adverse pregnancy outcomes. The findings suggest that exacerbation of air pollution and heat exposure related to climate change may be significantly associated with risk to pregnancy outcome in the United States.[xxxiv]

The impact of alcohol, tobacco, and other drugs on birth outcomes is well known, but less well known is that other toxic chemicals, including lead, mercury, pesticides, and chemicals found in air, water, food, and personal care products can increase risks for fetal death, infant mortality, pre-term birth, and low birth weight which put children at higher risk for learning, attention, and behavior disorders, as well as intellectual impairment. Unfortunately, we have an extremely limited understanding of exposure sources or cumulative exposures in part because there is inadequate monitoring of chemicals in people's bodies and in the environment; this is especially true of toxic chemicals in pregnant women, infants, and children. Federal investments in environmental health intervention and research have failed to match the urgent need to better address climate change and prevent cumulative exposures and impacts of toxic substances.

Given the high societal costs of inaction, lead hazard control is a critical long-term investment in our country's health.[xxxv xxxvi xxxvii xxxviii xxxix] Efforts need to be made to remove lead from consumer products and eliminate environmental exposure to all lead sources by pregnant women and infants.

IV. Migrant and Border Health

Concerns about the risks to pregnant immigrant women and infants at the southern U.S. border have become acutely evident.[xl] In just May 2021 alone Border Patrol apprehended 180,000 individuals on the southern border. Half are families and unaccompanied children. Currently, more than 1,000 unaccompanied children a week are apprehended there. In March and April 2021, the number was closer to 2,000 to 3,000 a day. The vast majority of families have been

turned away -- turned back to Mexico because of the Title 42 COVID protocols. Yet, tens of thousands of children and families have still been released into the United States. This number will undoubtedly increase dramatically when the COVID-19 protocols end. Currently, there are approximately 15,000 to 20,000 unaccompanied children who are in emergency intake shelters run by HHS, who are going to be reunited with their families.

Among the myriad issues facing immigrants, there are some specific issues that need to be addressed to assure the safety of immigrant pregnant women and infants. Even though the Maternal and Child Health Bureau (MCHB) of HRSA and other HHS programs have provided support to border communities, the needs are dramatically outpacing the resources that are available. There now exists an urgent humanitarian need to address the basic needs of immigrant families and transition them to more stable situations throughout the United States.

Among those basic needs not being met are the medical, social, and mental health issues facing families and unaccompanied children released into the United States. These services and programs available to address those needs are inadequate in scale and consistency and are uncoordinated. In addition, families often do not have access either because of restricted state programs or because access for these families is too difficult to navigate because of their recently arrived migrant status.

Many of the pregnant women and children being released into the United States have special healthcare needs and these individuals seldom get the services they require. Despite the fact that there are several networks of healthcare providers for children with special healthcare needs that have been formed, there is no organized HHS or MCHB support for meeting the special requirements of children entering the United States.

Compounding this is the lack of integrated capabilities to take care of children and families and unaccompanied children as they are apprehended by Border Patrol and Homeland Security agencies and transferred to HHS facilities. There is an urgent need to break down the silos between federal agencies and create integrated capabilities and facilities that bring together the law enforcement requirements of Homeland Security with the caretaking medical capabilities of HHS. HHS has the experience, the capability, the leadership, and staff with the expertise who can help broker these kinds of new innovative approaches that are desperately required. It is unconscionable that we have children in overcrowded Border Patrol facilities when there is a well-run HHS facility with expanded medical and custodial care capabilities available.

There are still children who under the zero-tolerance program of 2017/2018 were separated at the border from their families. It is estimated that there are nearly 1,000 children who have not yet been reunited with their families. Although special efforts are being made to reunite these families and thousands of families who have now been reunited, there is a desperate need of support services, mental health services, and particularly to address the needs of young children who were separated from their families and are still experiencing the sequela of emotional and mental trauma at that time.

ACIM notes there are specific, focused opportunities for the Department of Health and Human Services to reduce the risk of infant and maternal mortality among migrant children and families entering the United States. While ongoing efforts to enhance the capacity of the Office of Refugee Resettlement (ORR) remain essential, there is a related and urgent need for HHS to better organize the systems of care for immigrant pregnant women and infants at the border and for those dispersed throughout the United States.

V. Strengthening Data and Research for Action

In 1988, the Institute of Medicine (IOM) defined the core functions of public health as assessment, policy development, and assurance.[xli] Having high quality, current, and comprehensive data is essential in performing each of those functions. With the growing recognition of the impact of racism on the health of individuals in BIPOC communities the importance of collecting disaggregated race and ethnicity data has become evident.[xlii] Data systems should be established that help address the inequities in our society and advance health equity for all[xliii].

Data sharing and data integration to inform decision making across government entities is essential at every level—local, state, and federal. While most data sharing and integration occurs within a legal and governance framework, an emphasis on racial equity, transparency, and community engagement is often peripheral. This is especially troubling because government policies and programs that produce administrative data have often played a direct role in creating, enabling, and sustaining institutional and structural racism.[xliv]

In addition, too often technical experts and policy leaders do not value lived experience and at times have minimized the knowledge that community members hold—even when it may shed new light on pressing issues. To counteract this bias, we need to broaden and diversify the data/IT workforce and incorporate an equity lens for everyone who works with data. Organization and agency leaders and data stewards, managers, and users all have a duty to manage and use data responsibly and use it to advance health equity.

CONCLUSIONS AND RECOMMENDATIONS:

Adequately and effectively addressing the challenges facing infants, mothers, and women throughout their life course will require a comprehensive and sustained commitment to their health with a priority focus on addressing the inequities in all the systems that have led to the disparities in health outcomes that plague our society. Current U.S. maternal infant health outcomes are markedly worse than those in comparably resourced nations. Moreover, within the U.S., outcomes are far worse for BIPOC women and infants than for white mothers and babies. The COVID-19 pandemic, the climate crisis, and other environmental threats, along with border issues have enhanced the urgency and need for widespread transformations of all systems to optimally meet the needs of mothers and infants.

As the platform for all our recommendations, ACIM urges that all investment decisions and policy proposals, at all levels and sectors of government, be made with special concern for their impact on mothers and infants, and for women throughout their life course. ACIM also urges an immediate increased policy and investment focus on mothers and infants in our nation who are more likely to suffer suboptimal birth outcomes and poorer health over their lifetime. By addressing maternal infant health disparities, from pre-pregnancy through the year following delivery, ACIM's recommendations will improve maternity care systems and financing and strengthen workforce, data collection, and research. Our attention to environmental conditions and border health is in response to immediate additional threats to maternal and infant health.

Our goal is for U.S. maternal and infant healthcare to be of the highest quality and fully accessible for all. Moreover, ACIM's recommendations serve to advance birth equity; assuring the conditions of optimal births for all people, with a willingness to address racial and social inequities in a sustained effort. Attached is a list of recommendations that demands attention. This is not an exhaustive list of needed improvements in our current systems (notably lacking are recommendations related to childcare, family leave, and economic security) but rather a compilation of selected recommendations that are urgent, can be readily implemented, and will have an immediate impact on the health of mothers and infants.

ACIM's data-driven recommendations are grounded in our commitment to health equity and our shared belief that women of reproductive age, in collaboration with their healthcare professionals, are best able to determine the optimal care plan for their individual needs related to pregnancy. Our recommendations also recognize that the well-being of the communities in which women and infants live has a major impact on their health. Thus, wise and forward-thinking public policies in all sectors of our society that focus on the needs of mothers and infants are essential for improved birth outcomes. Knowing that the long-term health of our society depends on the health of mothers and babies, this focus will also serve as a platform for improving the overall long-term health of our society. Implementing the attached strategies will be a major step forward in helping to ensure the health and safety of all of America's mothers and babies during these challenging times and beyond.

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