RECOMMENDATIONS FROM ADVISORY COMMITTEE ON INFANT MORTALITY (ACIM) TO THE SECRETARY OF HEALTH AND HUMAN SERVICES

AUGUST 2021

ACIM believes that healthcare systems and essential physical, mental, emotional, and social support services for mothers and infants in the United States must be of the highest quality and fully accessible to all. Changes in current healthcare systems are necessary to meet this standard. ACIM also believes that the physical and social environments in which mothers and their infants live must be safe, secure, and supportive of healthy growth and development. This goal can only be attained by specifically addressing maternal and infant health inequities and disparities, particularly from pre-pregnancy through at least the first year after delivery and optimally throughout the life course of all women and infants.

Therefore:

ACIM recommends that all investment and policy decisions, at all levels and sectors of government, be made with special consideration of their impact on infants, mothers, and women throughout their life course.

ACIM recommends an immediate policy and investment focus on all mothers and infants in our nation, with increased investment and support to prevent pregnancy complications, adverse birth outcomes, and suboptimal health over their life-course, especially for mothers and infants who are members of Black, Indigenous, and People of Color (BIPOC) communities, and those who face additional challenges because of disability; wealth inequities; inadequate insurance coverage; insecure housing, homelessness, or residential segregation; or being undocumented, immigrants, or incarcerated.

The following set of recommendations focus specifically on maternity and infant care systems and financing, workforce expansion and diversification, environmental risks, and border health, and manifest the necessity to address racial and social inequities. These recommendations offer a pathway to advance birth equity and assure the conditions for optimal birth for all people. ACIM also recommends increased investment and support for data systems and focused research and evaluation to monitor and assess the impact of these recommendations on maternal and infant mortality and severe maternal morbidity.

I. CARE SYSTEMS AND FINANCING OF CARE:

The persistence and growth of inequalities in maternal and infant mortality requires more proactive and directive policy, programmatic, and financing strategies within the Department of Health and Human Services (HHS) to enhance access to and utilization of services and programs of known preventive efficacy.

1. Augment the Potential of Medicaid to Improve Maternal and Infant Health through Expansion of Postpartum Coverage:

- a) Extend Medicaid Coverage: Use Centers for Medicare and Medicaid (CMS) guidance and support through all potential mechanisms to continue eligibility (without redeterminations) for women following a Medicaid financed delivery, for at least one year.
- b) **Encourage Use of State Plan Amendments (SPA)**: CMS should issue timely and comprehensive guidance for states and accelerate approval of SPA submitted by states seeking to use the option created by the American Rescue Plan Act (ARPA) so that it has its intended impact on maternal health.
- c) Approve 1115 Waivers Provisions Related to Postpartum Coverage: For states that choose not to use the SPA option, CMS should facilitate and rapidly approve proposed state Section 1115 demonstration waivers provisions designed to extend postpartum coverage.
- d) **Support Maternal and Infant Dyadic Care**: In states where postpartum coverage extends to one year to align with automatic and continuous infant coverage for one year, provide guidance and technical assistance to states to improve coverage and care for the mother-infant dyad (e.g., mechanisms to ensure automatic and continuous enrollment of both mother and infant, maternal depression screening in well-baby visits, dyadic mental health therapy, and dyadic parenting programs).

2. Increase Funding and Improve Payment Models for Enhanced Perinatal Care:

Pilot and Disseminate the Findings of Alternative Medicaid Financing Models for Pregnancy Care: CMS through CMS Innovation Center (CMMI) should design, implement, and adequately fund pilot projects throughout the country that will test the cost, benefits, and limitations of alternative financing models for Medicaid financed pregnancy care, including group prenatal care. Findings of these pilots should be disseminated for replication and adaptation.

a) **Augment Telehealth**: Expand and sustain access to care through broad funding (including Medicaid) to telehealth via reliable broadband internet service for prenatal, early labor triage, and early and continuous postpartum and newborn care, including

- physicians, certified nurse-midwives and certified midwives, home visitors, home health workers, and doulas as a care team.
- b) Implement Risk-Appropriate Care: Encourage states to identify and follow established and evolving maternal and neonatal levels of care processes (Joint Commission, ACOG, CDC LOCATe) with the goal of identifying, supporting, facilitating, and improving antenatal care referral for high-risk mothers as well as fetuses who are identified with problems that may be treated in utero or who will need neonatal intensive care. Implement and expand reimbursement by CMS for referral and transport of high-risk mothers to higher levels of care, while supporting the back-transfer of recovering medically complex infants to local communities for continued convalescent care.
- c) Adequately Fund Indian Health Service Efforts to Reduce Infant and Maternal Mortality/Morbidity: Increase overall funding to the Indian Health Service in accordance with historical trust obligations between sovereign Tribes and the US government, with targeted funding beyond the \$5 million allocated in Fiscal Year 2021 to improve maternal and infant health outcomes.

3. Increase the Kinds and Number of Birthplace Options:

- a. **Expand Accredited Birth Centers**: Expand the availability, accessibility, and capacity of licensed and accredited free-standing birth centers as an option within a comprehensive system of care as recommended by the CMS, Health Resources and Services Administration (HRSA), and Administration for Children and Families (ACF) funded Strong Start Initiative.
- b. **Assure Information on Birthplace Options**: Pregnant individuals, especially those in under-resourced areas, should have timely access to accurate culturally and linguistically appropriate evidence-based health, safety, and risk information about their options for birth location as they consider where to give birth.
- **4. Strengthen Care Teams**: Provide logistical, technical, and financial support for community-based pre-pregnancy, prenatal, postpartum, and newborn care that is culturally and linguistically appropriate. This community care team approach requires the collaboration between physicians, midwives, doulas, and other community-based perinatal health workers to provide education and support during pre-pregnancy, pregnancy, labor, delivery, and post-partum periods. As the routine intrapartum care workforce and workflow does not facilitate maternity care team continuous presence, integration of doula care and/or continuous layperson support should be encouraged and supported.

5. Expand Existing Programs Known to be Successful in Improving Birth Outcomes

- **a. Expand the Healthy Start Program**: Expand the federal Healthy Start Program so that every jurisdiction which has an infant or maternal mortality racial disparity ratio of greater than 1.5 has adequate resources to implement a Healthy Start initiative.
- **b. Expand Home Visiting**: Expand the use of federal financing to HRSA for home visiting (including virtual visits and indicated and appropriate monitoring) for pregnant women, infants, and postpartum women for at least one year following delivery.
- **6. Prioritize Pregnant Women and Infants**: Encourage all HHS Offices of Minority Health (particularly the COVID-19 Health Equity Task Force, established by Executive Order 13995 on January 21, 2021) to prioritize pregnant individuals and infants in their deliberations related to COVID-19 and in their work on rural health care.
- **7. Improve Crisis Communication**: Develop and strengthen crisis communication strategies (using the COVID pandemic as an example scenario) that incorporate and respond to the unique needs of pregnant individuals, mothers and babies and their families during emergencies.

II. WORKFORCE RECOMMENDATIONS:

HHS should expand and strengthen the public health workforce dedicated to women's and infants' health through an enhanced policy and financing commitment to community-based providers such as public health nurses, nurse midwives, social workers, physicians, community health workers, and doulas. This workforce should be racially, culturally, and linguistically diverse and reflective of the communities served.

- 1. Expand and Diversify the Maternal and Child Health and Perinatal Workforce: Resources should be provided to establish, expand, and sustain the public health and community-focused workforce including community health workers, home visitors, public health and advanced practice nurses, physicians, doulas, navigators, lactation consultants, mental health specialists and others who care for and are trained to serve the Maternal and Child Health population, particularly low income, BIPOC pregnant women and infants and those with disabilities. Financing of this effort should include grants, scholarships, loans, and tax incentives and remuneration for working within communities with high perinatal morbidity and mortality.
 - a) **Expand the Use of Midwives**: Expand the use of certified nurse-midwives and/or certified midwives and allow them to practice to the full extent of their certification in all states and in all facilities.
 - b) **Fund Midwifery Training**: Commit sustained resources to support the education of certified nurse-midwives and/or certified midwives. Funds for midwifery training should be specifically directed to individuals from BIPOC, low-income, and rural communities to increase the diversity of the midwife workforce, improve its capacity to meet the needs of Medicaid beneficiaries, and better reflect the populations served.

- c) Explore Ways to Finance Doula and Community Health Worker Services: HRSA should work with CMS and state Medicaid programs to identify ways to fund the work of doulas and community health workers adequately and sustainably. In accordance with expert reports and historical recommendations, consideration should be given to adding doula services to the list of Essential Benefits of health plans offered through the Patient Protection and Affordable Care Act.
- d) **Fund Doula Training**: Establish a grant program to support doula training to increase the available doula workforce to support Medicaid/CHIP beneficiaries and uninsured pregnant people. Funds for doula training should be specifically directed to individuals from BIPOC, low-income, and rural communities to increase the diversity of the doula workforce and improve its capacity to meet the needs of Medicaid beneficiaries.
- **2. Assure Liability Protection**: Provide professional liability protections for the evolving, reconfigured maternity care teams—specifically for integration of non-hospital community-based care with hospital-based care and the expanding perinatal workforce.
- 3. Invest COVID-19 Response Funds in the Community Maternal and Child Health Workforce: Resources being provided to the states and other jurisdictions to sustain their COVID-19 responses should include substantial investments in services and personnel (physicians, community health workers, home visitors, public health nurses, doulas, navigators, etc.) focused on the needs of mothers and infants. Particular focus should be placed on augmenting BIPOC individuals in the maternal and child health workforce, with the goal of facilitating the option of race concordant care.

III. ENVIRONMENTAL CONDITIONS RECOMMENDATIONS:

HHS should play an expanded leadership and coordinating role in protecting infants and women - prior to and during pregnancy and lactation - from toxic environmental exposures.

- 1. Prioritize pregnant and breastfeeding women and infants in environmental research and policies: Commit and implement a major and sustained increase in research, funding, and policies aimed at protecting pregnant and breastfeeding women and infants from toxic and harmful environmental exposures in the air, water, food, and consumer products, especially for women and infants from BIPOC communities most burdened by cumulative exposures.
 - a) Expand Data and Monitoring Collaboration: Invest in, strengthen, and expand HHS agencies' collaborations with Environmental Protection Agency (EPA) to implement, house, and maintain the most up-to-date data to better identify communities at risk and invest and build upon the existing American's Children and the Environment Indicators.

- **b) Augment Biomonitoring**: Significantly expand and improve CDC and other federal biomonitoring programs with a special emphasis on pregnant women, infants, and children from BIPOC communities. Research should address intergenerational and transgenerational effects on health.
- c) Strengthen Research Collaborations: Partner with foundations (e.g., Kellogg Racial Equity 2030) and other public and private initiatives to fund a science-based Request for Application (RFA) that would address the environmental contributions to maternal and infant health and advance racial equity.

2. Prioritize the elimination of lead exposure:

- a) Eliminate Lead in Consumer Products (FDA): Direct Food and Drug Administration (FDA) to identify and eliminate all sources of lead in food, vitamins, cosmetics, and personal care products, with lead and other toxic metals in vitamins and baby food as a top priority.
- b) Eliminate Sources of Lead in Pregnant Women, Infants, and Children (HUD, EPA): Coordinate with other agencies, including Housing and Urban Development (HUD), IHS, and EPA, to swiftly implement a multi-pronged nationwide strategy to eliminate all sources of lead to protect the lives and health of pregnant women, infants, and children, especially those disproportionately exposed and impacted.
- **3.** Consider Infrastructure Equity Impacts: Assure that all infrastructure projects under policy and funding consideration or implementation that affect physical and social environments include a focus on equity and improving individual and community health.
- **4. Promote Restorative Justice**: Develop, implement, and support policies and programs to justly compensate community members who have been harmed by environmental contaminants.
- **5.** Include a Focus on Mothers and Infants in Responses to the Climate Crisis: All policies and legislation addressing the global climate crisis must include an assessment of the impact on women's health through the life-course and on birth outcomes, with mitigation plans to reduce those impacts.

IV. MIGRANT AND BORDER HEALTH RECOMMENDATIONS:

HHS must take immediate steps to improve its custodial capabilities and interagency coordination of systems directed at the medical and social needs of migrant children and families.

1. Enhance border community capabilities: Collaboratively construct and support local humanitarian capabilities in border communities to provide urgent, temporary assistance for families just released from Customs and Border Protection detention. This should include essential humanitarian requirements, including hot meals, clothing, and guidance regarding transportation to their respective destinations.

- 2. Establish New integrated Customs and Border Protection (CBP)/Office of Refugee Resettlement (ORR) Facilities: Provide leadership in exploring new, integrated facilities and procedures designed to meet the custodial and security needs of migrant pregnant women, infants, children, and families. DHHS should work with the Department of Homeland Security to create holding facilities that are specifically designed for pregnant women, infants, children and families and processing capacities that integrate ORR, CBP and Immigration and Customs Enforcement (ICE) personnel and expertise. ACIM appreciates the recent decision to reinstate ICE's presumptive release policy that applied to pregnant detainees.
- **3. Expand eligibility for service programs:** Enhance eligibility and support for medical, social, and mental health services for migrant women, children, and families and for programs and institutions that serve as trusted community partners for migrant families.
- **4.** Build a National Network for Migrant Pregnant Women and Children with Special Health Care Needs: Create and support a national network of obstetric and pediatric specialty care providers for pregnant women and children with special health care needs who are released
- **5.** Address Needs of Separated Children: Develop program to provide social and mental health services for migrant families that experienced child separations under the "Zero Tolerance" program during 2017-2018.
- **6. Focus Covid-19 Vaccines:** Support COVID-19 vaccine provision for migrant families entering the US, in accordance with CDC/FDA protocols.
- **7. Establish Portable Medical Records Systems:** Develop portable and interoperable medical records and registries and other real time data collection systems to document the needs of pregnant women, infants, children and families and children.
- **8. Support Research Initiatives**: Support the work of researchers, practitioners, and advocates to help develop the requisite elements of immigration policy that directly support the health of mothers and infants.

V. DATA AND RESEARCH FOR ACTION RECOMMENDATIONS:

HHS should take steps to strengthen and more effectively use data, information, and research to inform policies and programs for reducing inequities in access, quality, and provision of healthcare, social and environmental services, and inequalities in outcomes, for women and infants.

- **1. Strengthen Research and Data for Equity**: Invest in and promote the use of strengthened data sources, protocols, surveillance, evaluation, and research methods, and encourage and support scientists and researchers from diverse backgrounds.
 - a) Identify and document systemic and social inequities that adversely impact the lives and well-being of mothers and infants.
 - b) Measure the impact of structural racism, social inequities, and unequal treatment, on health care access, quality, delivery, and outcomes for women of reproductive age, pregnant and breastfeeding women, and their infants.
 - c) Expand traditional concepts and definitions of 'evidence,' with the valued inclusion of community voices and lived experience, especially of individuals from Black, Indigenous, and People of Color communities.
 - d) Engage with organizations, institutions, and entities that are underrepresented in the scientific workforce, to provide pathways for enhanced career development of individuals from BIPOC communities and other underrepresented groups in maternal and infant health data and information systems, surveillance, and research.
- **2. Enhance Data Systems, Interoperability, and Sharing:** Expand investments in robust and interoperable data and surveillance systems that enable sharing, analyses, and evidence-informed action, utilizing accepted data standards and best practices for data generation and stewardship.
 - a) Key data systems characteristic should include: i) uniform and standardized collection; ii) variables tracking both maternal and infant immediate and long-term health and well-being; iii) full collection and reporting of disaggregated race and ethnicity data; iv) social and environmental factors driving disparities in maternal and infant morbidity and mortality.
 - b) Data systems should include measuring access, quality and utilization of pre-pregnancy and perinatal care (e.g., treatments and preventive care- such as screening tests and vaccinations) for women and infants, by race and ethnicity, disability status, and by other factors that drive disparities and adverse outcomes (e.g., institutionalization, incarceration, border detention, homelessness/eviction; legal status).
 - c) Expand Pregnancy Risk Assessment and Monitoring Systems (PRAMS) and encourage greater harmonization of PRAMS with similar state-level pregnancy risk surveillance systems, to increase coverage to all states and territories.
 - d) Replicate state level surveillance and quality improvement innovations with known efficacy in improving maternal and child health, such as the California Maternal Quality Care Collaborative (CMQCC), so that other localities, states and/or federal systems might build from these models.
- **3. Augment Mortality and Morbidity Review:** Establish and adequately fund HRSA and CDC programs in every state that monitor and assess sentinel MCH-related morbidity and

mortality events, including Maternal Mortality Review Committees and Fetal and Infant Mortality Review committees.

- a) Provide technical assistance and support to strengthen collaboration between local sites, states, and nationally across maternal morbidity and mortality review, and fetal and infant mortality review processes, data, and findings. Support analysis of harmonized data and application of findings for action to decrease maternal mortality and fetal and infant mortality.
- b) Build capacity for the inclusion of qualitative data, lived experience, and family perspectives in sentinel event review approaches. Ensure that community voices are an integral component of the review process by requiring that review boards include individuals directly affected by fetal, infant, maternal mortality, or severe maternal morbidity. Support analysis of qualitative data to identify themes signaling opportunities to decrease maternal mortality and fetal and infant mortality.
- **4. Assure Inclusion in Research Affecting Women and Infants**: Prioritize inclusion or justify the exclusion of women of reproductive age, pregnant and breastfeeding women, and their infants in all health services research including vaccine and medication studies.
- **5. Monitor the Impact of Social Inequity During Emergencies**: Identify, document, and assess the impact of systemic disparities and inequalities of governmental responses to public health emergencies, with particular focus on the safety and well-being of pregnant women, mothers and babies and their families.

SUMMARY:

Adequately and effectively addressing the challenges facing infants, mothers, and women throughout their life course requires 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. Therefore, ACIM recommends that all investment decisions and policy development, 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 with 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.

ACIM's data-driven recommendations, formulated with a commitment to health equity and racial justice, recognize that the health of mothers and infants can only be protected and improved if they live in communities that are safe and supportive of their physical, mental, and emotional well-being with universal access to affordable, high quality, comprehensive, and culturally responsive healthcare. Implementing these recommendations will be a major step

forward in achieving that goal and helping to ensure the health and safety of all of America's mothers and babies during these challenging times and beyond.

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.

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