Progeny HEALTH®

An Unfair Fight

How Race and Social Determinants Impact Maternal and Infant Health

Third Edition

ProgenyHealth

ProgenyHealth is a national, tech-enabled women's healthcare company with over 20 years of experience, dedicated to improving outcomes across the maternity journey from early pregnancy through postpartum and parenting. With specialized expertise in managing high-risk pregnancies and NICU (Neonatal Intensive Care Unit) care, ProgenyHealth supports women, infants, and families during some of life's most critical and vulnerable moments.

Through a team of board-certified physicians, nurses, and social workers, ProgenyHealth addresses not only clinical needs but also the social determinants of health that deeply impact wellbeing. From connecting families to mental health resources, transportation, and healthy food, to providing baby essentials like diapers and clothing, our organization offers compassionate, hands-on assistance.

ProgenyHealth also helps families improve health literacy by educating them on care plans, doctor's instructions, and navigating the healthcare system. Our mobile app extends this support, offering direct access to case managers, pregnancy tracking tools, and parenting resources.

Whether it's developing personalized care plans for high-risk pregnancies or offering ongoing support after a NICU stay, ProgenyHealth is committed to reducing disparities, enhancing the care experience, and ensuring that every family has the tools they need for a healthy start.

DIAGNOSED DIABETES

4.7%

Diabetes is diagnosed higher in Black adults compared to white adults

PROSTATE CANCER

2.1x

Black men are more likely to die from prostate cancer than white men

BREAST CANCER

40%

Increase in mortality for Black women, compared to white counterparts

There is a mountain of data that shows Black, Asian American, Pacific Islander, Native American, Alaska Native, and Latinx individuals are disproportionately likely to experience adverse health problems. Compared to white adults, the rate of diagnosed diabetes is 4.7% higher in Black adults, who are also more likely than their white counterparts to develop dementia later in life. Black men are 2.1x more likely to die from prostate cancer than white men, and breast cancer mortality among Black women is 40% higher than that of white women, even though white women are almost 2% more likely to develop breast cancer in the first place.

LEARN HOW YOU CAN MAKE MEANINGFUL CHANGE TODAY.

These trends hold true for the COVID-19 pandemic, which has helped reveal and reinforce social, economic, financial, and health related inequities. Black Americans are experiencing 5% higher case numbers and 2x more fatality from the virus compared to white Americans. During this period, the maternal mortality rate increased yet again, with a 14% year-over-year increase during the first 12 months of the pandemic. Here too, the disparities are significant: the mortality rate among Black women is 2.6x that of white women.

While these data points are linked to an individual's race, and are helpful for tracing general health patterns, they obscure the underlying cause: race as a social construct that has narrowed access to resources and opportunity. This is an important distinction to be drawn. **While race itself does not impact health, the experience of racism undeniably does. As the introduction merely begins to demonstrate, the effects are pervasive.**

While health disparities have permeated every level of healthcare, this action plan **focuses specifically on their lasting impact on infants and their mothers**. More specifically, it focuses on the starkest disparities – those seen in Black maternal and infant outcomes. It explores the connection between race, ethnicity, social determinants of health (SDOH), implicit and explicit bias, internalized stress, and the resulting effects on the mother-infant dyad through pregnancy, at birth, and beyond the first 1,000 days. Ultimately, it offers a critical path forward to ensure a more equitable system for all mothers and their newborns.

A "Socially Transmitted Disease"

The impacts of racism trickle down generationally. In an interview with the *New York Times*, Dr. Maria Trent, a professor of pediatrics at Johns Hopkins School of Medicine, said of racism: "We call it a socially transmitted disease: It's taught, it's passed down, but the impacts on children and families are significant from a health perspective."

And they have been for a long time. Disparities in white-Black infant survival rates are not new: they reach back, at least, to 1850, when the United States first started collecting records by race. What is new is how rapidly the divides are growing. In 1850, the Black infant-mortality rate was 340 per 1,000, while the white rate was 217 per 1,000. Today, Black infants are more than twice as likely to die as their white counterparts: 10.8 per 1,000 Black infants, compared to 4.6 per 1,000 for white babies. It is critical to note that Native Hawaiian or other Pacific Islander populations, and American Indian and Alaska Native communities see similarly high infant mortality rates, at 9.4 deaths per 1,000 births and 8.2 deaths per 1,000 births, respectively.

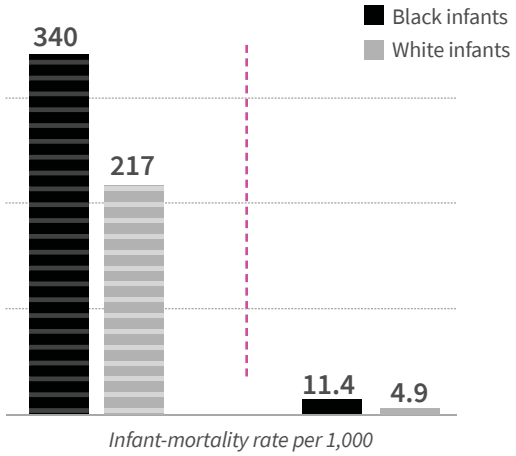
Infant death is only one side of the story. In the United States, maternal mortality has been on the rise since 2000. When compared to 10 similarly wealthy, developed nations, the US ranks worst in maternal care, and has the highest rate of maternal death.

These pregnancy-related deaths affect Black women worst of all, with a maternal mortality rate 3x higher than that of white women. The rate is over 2x higher among American Indian and Alaska Native women. Among that population living in urban areas, that rate increases to 4.5x higher.

According to the CDC, the two leading causes of maternal death are high blood pressure and cardiovascular disease. Related hypertensive disorders in pregnancy, such as pre-eclampsia and eclampsia, are 60% more common - and more catastrophic - in Black American women. Gestational diabetes, which is often correlated with pregnancy complications, is most prevalent among Asian/Pacific Island mothers, at 14.8%. These conditions are largely preventable—by one committee's estimate, 80% of pregnancy-related deaths were preventable, regardless of race or ethnicity. To address these catastrophic outcomes, we must first address the web of racial and ethnic disparities, including SDOH and existing health inequities, that help drive them.

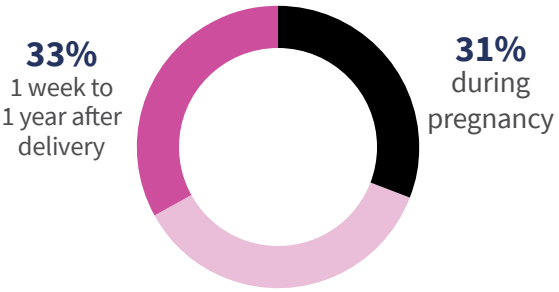
Disparities in white-Black infant survival rates

1850 VS **Today**



American Indian and Alaska Native populations see similarly high infant mortality rates, at **9.2 per 1,000 AI/AN** infants

Pregnancy-related deaths occur during pregnancy, delivery, and postpartum

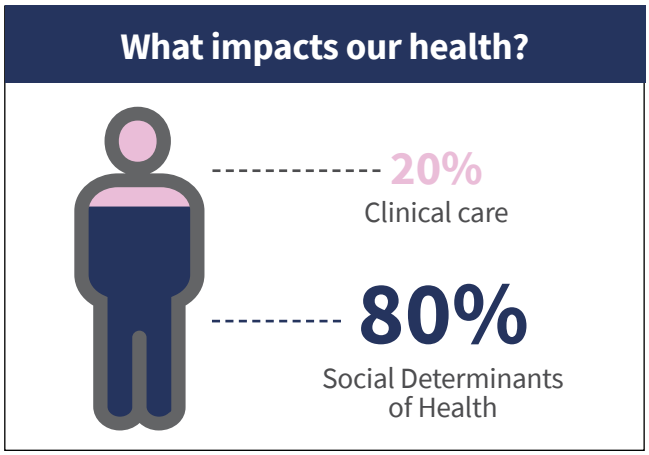


Source: CDC

> Traditionally, nobody has owned social determinants - it was always presumed that someone else would fill in those gaps.
>
> — Dr. Ellie Stang, ProgenyHealth CEO

Disparity Drivers: Social Determinants of Health are Only Part of the Story

Social determinants of health (SDOH) are a broad framework of non-medical social, environmental, and economic conditions that are known to contribute to population health outcomes. These determinants include factors related to economic stability, education, social and community context, health and health care, and neighborhood and built environment. Recent studies work to quantify the outsized impact these factors have. They estimate that 20% of a population's variations in health outcomes are related to clinical care, while 80% are influenced by social factors and the environments in which people are born, grow, live, work, and age.



While it is tempting to look only at social determinants of health, research suggests this would create an incomplete picture. It turns out that possessing advanced degrees, having access to financial security and the best healthcare, or being under the bright light of media coverage, cannot prevent catastrophic outcomes for otherwise young and healthy Black women.

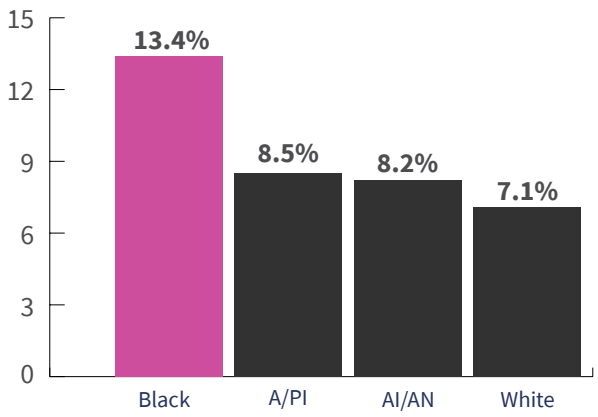
Famously, tennis superstar Serena Williams fell short of breath after an otherwise routine delivery of her baby girl. Despite a dedicated care team, a well-documented history of pulmonary embolism, and her persistent requests for CT scans and blood thinners, she felt her concerns were initially dismissed. By the time her requests for more urgent care were granted, she had already developed a pulmonary embolus, needed blood thinners and had a very prolonged postpartum recovery. As a result, her first six weeks of motherhood were spent recovering from a serious medical condition that she believes could likely have been lessened or prevented.

Ms. Williams' story may even be considered lucky in the context of those that follow. Myriad other high profile and accomplished Black women who had climbed to the heights of personal success still failed to receive the necessary level of attention and care for successful and healthy deliveries. CDC epidemiologist Dr. Shalon Irving died of complications from high blood pressure just three weeks after giving birth. Kira Johnson, linguist, marathoner, and daughter-in-law of the nationally syndicated Judge Hatchett, began internally hemorrhaging after delivery, and failed to receive the life-saving care she needed. According to her husband, the delivery team could not see Kira the same way they would see their own kin. He recalls one nurse aide's frank admission: "[She] just isn't a priority right now." By the time she received surgical attention, it was too late.

All three tragic deaths underscore the larger issue. Black mothers are dying – or experiencing pregnancy related complications – at an unacceptable rate. In a speech before Congress, Wanda Irving, Shalon Irving's mother, translated a known CDC statistic into a staggering percentage. She said: "Let me spell this out another way… Black women are 243% more likely [than white women] to die from pregnancy or childbirth related causes." In the cases of Dr. Irving and Ms. Williams, their medical histories were well documented. In Kira Johnson's case, her urgent requests for necessary care went unheard. Many maternal deaths are likely preventable, and these women's stories illustrate the need to reinforce proper care prior to, during, and after delivery.

Academic evidence helps underscore this imperative. A Black woman with an advanced degree is more likely to lose her baby than a white woman with less than a high school education. Even when the education levels are equivalent, the risks are still outsized for Black women: infants born to college-educated Black parents were 2x as likely to die as infants born to similarly educated white parents. The research indicates low birth weight is the culprit 72% of the time, and disproportionately affects Black infants. Importantly, studies have proved that race or genetics alone are shown to have nothing to do with low birth weight.

Low birth weight by race in US (2017 – 2019)



A/PI - Asian/Pacific Islander
AI/AN - American Indian / Alaska Native
Low birth weight is less than 2500 grams/5.5 pounds
Source: March of Dimes:

Weathering, and The Outsized Impact of Stress

When tracing causes of higher incidence of premature births, maternal complications, and infant mortality, SDOH alone cannot account for these discrepancies, nor can genetics. More recently, scientists are positing that stress plays a major factor in long term health. The groundbreaking "weathering" hypothesis posits that the cumulative effects of discrimination, along with social and economic disadvantage, result in very tangible declines in health. In effect, science is proving that discrimination itself is bad for one's health.

These studies point out that no other cause properly explains the poor pregnancy outcomes in Black women. An outdated line of thinking correlates higher rates of teenage pregnancy with higher rates of infant complication and/or mortality. Yet, youth isn't the culprit—risks are higher in Black women the later they wait to have children. Perpetual poverty isn't the answer—see Beyonce's high-risk pregnancy experience with her twins. As noted earlier, lack of education isn't the reason either. What is pervasive, and contributes to risk factors for complicated pregnancies, like diabetes, hypertension and stroke, is the body's physiological response to repeated and intensifying episodes of racism-related stress.

For many, stress begins in childhood: 61% of adults surveyed across 25 states report experiencing at least one form of an Adverse Childhood Experience (ACE). Stress is even more pervasive in a large portion of the population. Of those studies, one in six report experiencing four or more different types of ACEs. Studies now link ACEs, including experiencing episodes of violence, abuse or neglect, or household instability due to incarcerated family members, mental illness, substance abuse, or other traumas, to long lasting health problems, mental illness, and increased risk for substance abuse as an adult. In fact, the National Scientific Council on the Developing Child coined the term "toxic stress" to describe the excessive activation of stress response systems on a child's developing brain and body—and its resulting long term wear-and-tear.

While evolutionarily, a little stress is meant to be helpful, chronic stress is detrimental, especially for pregnant women. An overexposure to stress hormones can cause biological damage, known as allostatic load. While more research must be conducted to pinpoint the extent of weathering's role in Black maternal mortality and medically complex births, this damage is thought to be a key player in the low birth weight rates of Black infants, and in the comparatively high Black mother mortality rates.

> We need to work toward coverage across all stages of motherhood, from planning and prenatal care, through pregnancy, a healthy delivery, and to at least one year postpartum. If we can make sure a mother gets everything she needs for a healthy pregnancy, you're saving future lives."
>
> — Dr. Ellie Stang

Breaking The Cycle

While the path ahead is undefined, measured steps must be taken to address the maternal-fetal health continuum and pave the road toward health equity. Acknowledging racism as a social and economic construct is an imperative first step. Prominent healthcare institutions began issuing proclamations in 2020 and 2021 to "dismantle racism at every level," including: The American Academy of Pediatrics, The American Medical Association, The American Public Health Association, The American College of Obstetricians and Gynecological Health and The American Psychological Association, just to name a few.

Most recently, the Biden-Harris Administration released the Blueprint for Addressing the Maternal Health Crisis, which engages all branches of government within the call to reduce maternal mortality. The plan's ultimate goal is to establish the United States as the world's safest country in which to have a baby. It outlines five tangible goals, which focus on increasing access to and the availability of comprehensive, high-quality maternal care services, and identifies myriad opportunities to designate high-caliber care centers, including identifying "Birthing Friendly" hospitals and those with doulas and midwives.

These additional social measures help communicate the urgent need for change, and build on the HHS Action Plan's steps to improve maternal outcomes by 2025. These quantifiable goals include: reducing maternal mortality rate by 50%, reducing low-risk cesarean deliveries by 25% and achieving blood pressure control in 80% of women of reproductive age with hypertension. Notably, the plan acknowledges the importance of embarking on a comprehensive, "life course" approach, which includes addressing the role that social and economic risk factors play in maternal and newborn outcomes. The department is making an effort to pursue partnerships with impactful organizations, like The March of Dimes, to address disparity gaps in maternal health outcomes for Black women, along with other agencies in order to help raise awareness of postpartum complications. These partnerships help amplify the message and empower more grassroots organizations to make greater impact.

More broadly, to help reduce implicit and explicit bias in healthcare, it is essential to continue spreading awareness of the invisible, yet marked, ways in which racism impacts people of color. Sensitivity and bias training are great ways to help build strong practice workplace cultures and help staff recognize and combat classic signs of implicit bias at the clinical level. It is important also to understand, address, and fill for care gaps due to the broad structural impacts of factors, like SDOH. Access to safe housing, food security, quality education, improving health literacy, and epicenters of care are baseline quality of life factors that play a critical role in health and well-being through every stage of life.

HHS action plan with steps to markedly improve maternal outcomes by 2025.

- Reduce maternal mortality by **50%**
- Reduce low-risk Cesarean deliveries by **25%**
- Achieve blood pressure control in **80%** of women of reproductive age with hypertension

> I'm hoping ProgenyHealth will be a leader in working toward health equity. We're at the forefront, trying to move the needle, solving for care gaps in whatever ways we can by partnering with others, connecting the dots for care. We have excellent healthcare in this country, we need to be sure everyone can access it. The time is now, it really is."
>
> — Dr. Ellie Stang

A Framework for Tangible Impact

At ProgenyHealth, we believe we have a collective responsibility to address this pervasive problem facing people of color from the beginning of life: the severe impact of racism-induced stress on maternal and infant health. To help formalize how we can create change together, we have outlined tangible steps that healthcare stakeholders – in partnership with public policymakers and local organizations – can take to reduce the adverse impacts of systemic bias, SDOH, and health inequities on mothers and their infants.

WHAT PROVIDERS CAN DO

- **Engage:** As the cornerstone of healthcare, providers can engage patients at every step of their journey to motherhood. By working to understand your patient's socioeconomic stability and medical history, the better you can forge a relationship that can help actively combat feelings of stress and isolation she may be facing. Help destigmatize screenings by routinely conducting them with all patients, and in a sensitive, empathetic and caring way. Standardized workflows can help your practice understand risks from SDOH, address care gaps, and support your patients through healthier pregnancies. For example, the American Academy of Family Physicians has created a set of resources called The EveryONE Project Toolkit to assist physicians and their care teams. It includes educational materials on implicit bias training, bettering practice culture of health equity, standardized SDOH screeners and assessments, and more.

- **Open up your care team:** More than 25% of Black women meet their birth attendants for the first time in the delivery room, compared with 18% of white women. One in five of these women reported poor treatment from hospital staff on the basis of race, ethnicity, or language. These experiences and their associated risks are becoming prevalent enough to motivate a new spike in community births. From 2019 to 2020, the percentage of these non-hospital births increased by 20% YOY, with the biggest increase seen among Black women at 30%. Amongst healthy women, the research indicates better results, indicating that the impact of a personal ally and a safe space cannot be understated. The doula model offers women from underserved communities a lifeline to additional medical and emotional support during pregnancy, through labor, and over their first weeks as new mothers. A five-year analysis of one Brooklyn program showed that mothers receiving doula support had half as many preterm births and low birth weight babies as other women in their same communities.

  Similarly, when midwives are included as part of the care system, mothers and families experience better outcomes. Currently, only 10% of U.S. births involve a midwife, which is much lower than all other industrialized nations, where midwives play a role in half or more of all deliveries. A recent study correlated the significant impact that a high density of available midwives had on birth outcomes by state: Those states with higher midwife integration scores saw significantly lower rates of preterm birth and low birth weight babies, and higher rates of successful vaginal deliveries, even in women who previously delivered via C-section. The impacts reach beyond delivery as well—states with high midwifery rates saw the highest national rates of breastfeeding at birth and at six months of age. Improving access to and integration of midwives in states with high rates of Black births and neonatal mortality can make a marked impact on outcomes for families.

- **Expand programming through partnership:** Programs reduce healthcare costs by addressing disparities head on. Malnourished patients cost health systems nearly twice as much due to prolonged recovery times and higher hospital readmission rates. To help address nutritional deficiencies, Chicago-based Advocate Aurora Health introduced regular malnutrition screenings at intake. Those with elevated risk scores received supplements and nutritional advice for post-discharge. In just six months, the program reduced healthcare costs by $3,800 per patient, for a total of $4.8 million in savings. Hospital-housing partnerships also have big impacts. A recent program run by the University of Illinois in partnership with the Center for Housing and Health worked to find stable housing for at-risk patients. Those participating saw healthcare costs fall between 42% and 61%.

WHAT HEALTH PLANS CAN DO

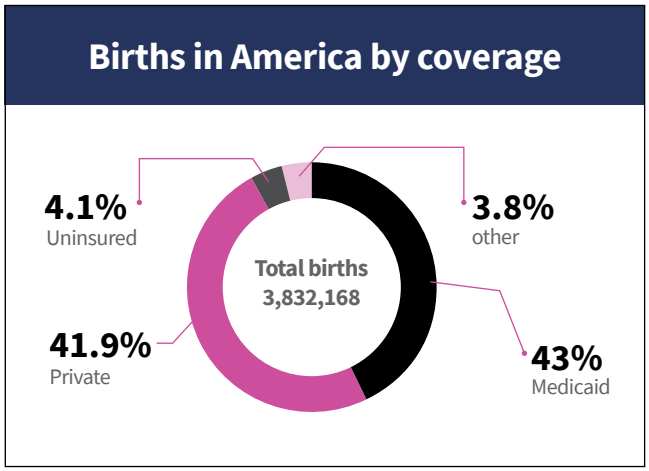
- **Standardize SDOH codes:** By building billable codes into your repertoire, clinicians can start to actively collect, monitor, and act to help fill care gaps for patients with clear risk factors. In 2018, the CDC adopted a series of ICD-10 Z codes specifically related to SDOH. The hope is that widespread adoption of these codes, especially if they are expanded to include barriers to care, can begin to provide a more robust picture of the health risks and factors in patients' case histories.

- **Enable Direct Claims Reimbursement:** Yet, without direct claims reimbursement, these ICD-related efforts can only go so far—current coding and billing standards mean organizations are losing money on their SDOH programs. A recent survey of hospital executives uncovered that over 57% of respondents self-fund programs through decremental budgets. The path to direct claims reimbursement must be clearly outlined to garner increased and consistent buy-in from hospitals and health systems, who would be able to address disparities head-on.

- **Identify trusted partners:** Maternal and infant mortality are key health indicators in all developed nations. There is a strong need to build strong responses to critical situations; expert care is needed to provide experience on how to manage critical cases when they arise without requiring undue burden on the hospitals themselves. Health plans should rely on dedicated partners to support maternity and NICU case management and look to innovative programs to help support women of all races.

WHAT POLICY MAKERS CAN DO

Efforts are finally being made on a national level. The U.S. government has acknowledged the untenable impacts associated with health inequity. In December 2020, the Department of Health and Human Services launched *Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America*, a wide-ranging initiative centered on the vision of making the United States one of the safest countries in the world for women to give birth. It outlines three aggressive goals with a target date of five years and an action plan for achieving them. Importantly, it identifies federal funding of $116 million to invest in critical areas, including expanding Maternal Mortality Review Committees (MMRCs), expanding perinatal quality collaboratives (PQCs), and investing in better access to care and reduction of disparities.



While promising, there is still much to be done on both the state and local levels:

- **Leverage Medicaid Expansions:** Medicaid plays an out sized role in maternal care: in 2024, 41% of all U.S. births were covered by the program. Legislators on the state level can pull many levers to help shape Medicaid policy as it relates to maternal care, including: the duration of pregnancy-related coverage, the benefits included, and more. Most Medicaid Plans currently cover new mothers for 12 months after delivery - a window that is now sufficient for postpartum care.

Expanding Medicaid for all women up to 138% of the federal poverty level has had wide-ranging impacts—the 41 states plus DC that expanded their coverage under the Affordable Care Act saw 1.6 fewer deaths per 100,000 women than states without expansion. However, in the states that have

not opted in, many new mothers are left vulnerable and become uninsured just two months after giving birth. As one-third of all maternal deaths occur in the postpartum period, expanding access to ongoing care and support is critical for better outcomes. Extending care to include regular visits, preconception care, and postpartum check-ups can make all the difference by identifying early on risk factors that most often lead to maternal mortality, like obesity, diabetes and heart disease.

As of this publication, many states have adopted the landmark American Rescue Plan's Medicaid state plan amendment, which offers pregnancy-related Medicaid and CHIP coverage for one year post-delivery. For the states that opted-in, benefits became available to new mothers as of April 1, 2022 and will extend through March 31, 2027. As a first step, this is an important one to ensure that states can support their most vulnerable populations. Over the next few years, much work must be done to monitor and socialize the expansion's impact to help bolster the case for permanent extended coverage for all new mothers across all 50 states.

- **Advocate for and Help Fund Local Clinics:** Local clinics help provide access to birth control, family planning resources, STI testing and treatment, Pap tests, and reproductive health care. When their existence is threatened, there are tangible impacts on maternal outcomes. In fact, much of America's women are without easy access to reproductive care. A March of Dimes report revealed that about 35% of all US counties are "maternity care deserts," which means in those areas, there are zero hospitals, birth centers and certified nurse midwives to provide OB care. This impacts an estimated 2.2 million women of childbearing age and nearly 150,000 births annually. As the majority of clinics are one of the only access points for OBGYNs in many remote parts of the country, clinics fill a critical need for empowering health education and literacy, and access to reproductive care.

- **Sponsor Community Programs:** While directional spending and funding needs to come from the federal level, communities have the best perspective on and understanding of what is needed to make measurable improvements in maternal and infant care. Access to care should be a priority: in 2016, over half of all counties had either limited or no access to hospital-based OB services or providers. Volunteer doulas offer resources, education, emotional support, and active listening—early studies indicate community doula programs vastly improve outcomes for both mother and baby. Telemedicine and health monitoring apps help share education information and track nutritional intake, pregnancy milestones and more.

> "When access issues arise, they must be approached through the lens of "this is a mom and a baby." It doesn't matter who you are, what your finances are, where you live, what you look like, or what your background is. Regardless, all moms deserve the same access to care. We must train our teams to solve these access issues when they are identified."
>
> — Dr. Ellie Stang

In Conclusion: Taking Action

At ProgenyHealth, our singular focus is to help improve the rates of healthy newborns and new mothers through data-driven insights that power provider collaboration and parental impact. We focus on mothers and their infants in order to address health inequities and ensure that the highest quality of care is extended to everyone.

This paper set out to highlight the current discrepancies in maternal care and newborn outcomes for different populations in the United States, in order to amplify the stark realities that exist for Black, American Indian, Alaska Native, Asian American, Pacific Islander, Latinx, Hispanic, and all women of color. By acknowledging the lack of and need for health equity, we can align ourselves on a path to delivering quality and consistent maternal care for women of all races and ethnicities, across the entire spectrum of new life, from family planning through to pregnancy, and into the experience of new motherhood.

We believe in providing this full continuum of care to holistically support mothers and their newborns from conception through to a full year post-delivery, as a necessary foundation for a healthy start to life. Regardless of method, our goal is to achieve quality outcomes that protect our mothers and the most vulnerable among us, our newborns. We can tailor outreach by circumstance, and ensure all mothers and newborns have a safety net for care and community.

We call on our community leaders, industry partners, and governmental influencers to take tangible action.

Working together, our clinical delivery and policy bodies—whether they be providers, payors, community activists, or political leaders—can make a difference in the future lives of an entire population of infants and their mothers, if we move forward in lock-step.

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