American Academy of Pediatrics

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Statement of
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On behalf of the
American Academy of Pediatrics

Before the
U.S. House of Representatives
Committee on Energy and Commerce
Health Subcommittee

"Legislation to Improve Americans' Health Care Coverage and Outcomes"

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Good morning. Chairwoman Eshoo, Ranking Member Burgess, and members of the subcommittee, it is my pleasure to be here today to address vitally important legislation to advance and protect child health. My name is Dr. Lee Beers and I am a pediatrician and the president-elect of the American Academy of Pediatrics (AAP). I am here today officially representing the AAP, a non-profit professional medical organization of over 67,000 pediatricians, pediatric medical subspecialists, and pediatric surgical specialists across the United States. In addition, I am an Associate Professor of Pediatrics at Children's National Hospital here in Washington, DC, where I serve as the Medical Director of Community Health and Advocacy in the Child Health Advocacy Institute. I also co-direct the Early Childhood Innovation Network, a local collaborative that works to promote the healthy development of young children who are exposed to early childhood adversity.

Thank you for holding this hearing today on a number of bills to improve health outcomes and coverage. Today, I will speak to two of them: the Scarlett's Sunshine on Sudden Unexpected Death Act (H.R. 2271) and the Healthy Start Reauthorization Act (H.R. 4801). The AAP strongly supports both pieces of legislation. Together these bills will help reduce infant mortality, prevent sudden unexpected infant death, and promote healthy child development.

Scarlett's Sunshine on Sudden Unexpected Death Act

I will first discuss policy opportunities to address sleep-related infant and child deaths through the Scarlett's Sunshine on Sudden Unexpected Death Act. The AAP endorsed this important bipartisan legislation as a key component of a comprehensive federal policy agenda to protect more children and prevent more families from the tragedy of losing a child. This is an issue of critical importance to the Academy, and we appreciate the Committee's ongoing efforts to prevent and address these fatalities through this and other related legislation.

Sudden unexpected infant deaths (SUID) are those occurring among infants younger than one year of age where the cause of death is not obvious before investigation, often occurring during sleep. Sudden unexplained death in childhood (SUDC) refers to the death of a child older than 12 months, which remains unexplained after a thorough case review. The Centers for Disease Control and Prevention (CDC) estimates that in 2017 there were approximately 3,600 SUID cases, and that SUDC affected approximately 243 children between 1 and 4 years of age.[1]

In the 1990s, the AAP introduced its revised safe sleep guidelines recommending supine—on the back—sleep positioning. The AAP also partnered with government agencies on the successful Back to Sleep campaign. These efforts generated a major public health advance in the form of a substantial decline in SUID, from over 150 SUID cases per 100,000 live births in 1990 to 93.4 SUID cases per 100,000 live births in 2017.[2] However, we have seen very little progress in reducing SUID in a decade or more, and these numbers remain unacceptably high. There also remain large disparities in the incidence and prevalence of SUID and SUDC based on race and ethnicity, with disproportionately high rates among black and Native American families. This is a significant public health issue necessitating a multifaceted approach to best understand the problem and effectively address it.

As a pediatrician, I know that questions related to sleep are at the top of any new parent's list when they come to see me. The guidance I give parents is critical to promoting safe sleep practices, but it alone will not suffice. Parents want to know why I am making these safe sleep recommendations, and to understand why they are so important 100 percent of the time when frankly, they may be receiving differing advice from family members or feeling so desperately tired they think, "I'll bring my baby in bed with me just this one time". We need to

better understand why infants and young children continue to die during sleep, and how we can prevent it through policy reform and revised clinical practice and anticipatory guidance. Scarlett's Sunshine offers a major opportunity to make significant progress in reducing sleep-related deaths. I'd like to highlight key provisions of the bill that the AAP believes are essential to this work.

Scarlett's Sunshine would authorize $8 million annually to improve and standardize death scene investigations and autopsies, and $2 million annually to support training to implement those approaches. This would entail new guidance for better data reporting on circumstances surrounding SUID and SUDC, and grants to states to support the completion of comprehensive and standardized death scene investigations and autopsies. Because progress has plateaued on reducing sleep-related fatalities, it's vital that we better understand risk factors to prevent future deaths. We need to know if the problem is that we still are not reaching enough families with education about safe sleep, if that education needs to be reframed to address different cultural or socio-economic considerations, if infants are in particular unsafe sleep environments such as an inclined sleeper or a crib with bumpers and soft bedding, or if yet another factor is still contributing to sleep-related deaths. This approach would help us better understand SUID and SUDC, ultimately enabling pediatricians like me to best tailor our guidance to families to prevent these tragedies.

In addition, the bill would support the vital work of child death review teams. Pediatricians around the country serve on child death review teams, which can operate either locally or statewide. This is essential work that studies the sentinel events of unexpected child deaths to understand how to prevent such fatalities in the future. Unfortunately, these teams often operate with little to no funding support, and the scope and breadth of their work varies significantly nationwide. Scarlett's Sunshine would authorize $15 million annually for states and localities to build capacity to review 100 percent of all infant and child deaths. The bill's provision to enhance the CDC's National Fatality Review Case Reporting System would draw upon these efforts and further support evidence-based policymaking to prevent child deaths.

The bill also would take critical steps to better meet families' needs in preventing and responding to sleep-related deaths. The authorization of $5 million annually for the promotion of evidence-based safe infant sleep would support prevention approaches including home visits, public education campaigns, and the provision of safe sleep products like cribs and play yards to low-income families. The AAP particularly appreciates the bill's clarity on the types of guidance and products these grants would provide, to ensure they adhere to safe sleep guidelines. It's critical that these resources only promote the use of safe sleep environments, especially given the proliferation of untested and often dangerous sleep-related products, including crib bumpers, inclined sleepers, and in-bed sleepers. In addition, we strongly appreciate that the bill would authorize $1 million annually for parent support services, like grief and bereavement counseling. Losing a child is the deepest grief a parent can imagine, and these are essential services to help them in their time of need. I still remember like it was yesterday—twelve years ago, when pregnant with my own son-consoling a father in the emergency department who was cradling his infant son, who had just been lost to Sudden Unexplained Infant Death. And then, the feelings of helplessness, and even anger, I felt afterwards when despite our best efforts, our team was unable to identify timely and accessible grief counseling for this unimaginably suffering family.

I'd like to also note that the AAP strongly supports the Committee's leadership in advancing legislation this year to ban dangerous crib bumpers and inclined sleepers like the recalled Rock 'n Play. We appreciate that the full U.S. House advanced these policies together in the *Safe Sleep for Babies Act* (H.R. 3172), and we continue to urge the Senate to pass that legislation without delay. The enactment of Scarlett's Sunshine will build on the

Committee's leadership in preventing infant and child fatalities, and we urge the Committee to advance this important legislation as written.

Healthy Start Reauthorization Act of 2019

I will now turn to the Healthy Start Reauthorization Act of 2019. In the United States, infant mortality – defined as the death of a child before his or her first birthday – has been declining. Nationally, the infant mortality rate fell by 14 percent between 2007 and 2017.[3] Since 1991, Healthy Start has played a critical role in this effort to reduce infant mortality rates across the country. Healthy Start aims to improve birth outcomes by working to ensure that women living in communities with infant mortality rates at least 1.5 times the national average have access to early prenatal, postpartum, and infant care. It serves women of reproductive age, pregnant women, postpartum mothers, and infants and families from birth until the child is 18 months old. Each family enrolled in the program receives a comprehensive assessment that considers physical and behavioral health, employment, housing, domestic violence risks, and more. While known for the prenatal care it provides, the program also offers many other support services like case management, home visiting services, parenting skill-building, transportation, child-care, and breast feeding and nutrition support, to name a few, as well as provider training.

However, despite recent reductions in the national infant mortality rate, significant inequities unfortunately remain. The mortality rate for infants born to non-Hispanic black mothers is more than twice as high as that for infants born to non-Hispanic white mothers.[4] Non-Hispanic black mothers also have the highest rates of preterm birth and low birth weight among all racial and ethnic groups.[5] Moreover, the mortality rate remains higher than average for infants born to Native American, Alaska Native, and Pacific Islander mothers.[6] These rates are evidence of worrisome infant health disparities and deserve our attention. Healthy Start attempts to alleviate this problem through providing intensive and culturally sensitive parent support. In addition to reducing infant mortality rates overall, Healthy Start aims to reduce racial and ethnic disparities among birth outcomes. The prevalence of these infant health inequities underscores the continued need for Healthy Start programs in vulnerable communities.

Maternal mortality is also a serious, ongoing crisis in the United States. According to the CDC, the national rate of maternal mortality has more than doubled between 1987 and 2016.[7] Alarmingly, black women, Native Americans, and Alaska Natives are two to three times more likely to experience pregnancy-related deaths regardless of socioeconomic status. Studies indicate that more than half of these deaths are preventable.[8] Again, these staggering statistics illustrate the importance of reauthorizing Healthy Start. Along with improving infant health outcomes, Healthy Start seeks to reduce maternal mortality rates and improve women's health before, during, and after pregnancy.

As a pediatrician in Washington, DC with a focus on community pediatrics, I have seen firsthand the need for and the positive impact of programs like Healthy Start. My experience is that every family wants the best for their child but sometimes doesn't have the support they need to ensure their child grows up in a safe and stable home with access to quality education. Mothers, infants, and families greatly benefit from the connection to resources that may not otherwise be available to them, including health care services such as prenatal care, enabling and social services such as case management and child care, and public health services such as immunization and health education. Healthy Start also supports provider training to help ensure that patients receive targeted and appropriate comprehensive services no matter where they receive their care.

Here in Washington, DC, there are great inequities in access to needed prenatal care and wide disparities in birth outcomes. For example, according to a Perinatal Health and Infant Mortality Report issued in April 2018 by the DC Department of Health, for the period covering 2006 through 2016, the percentage of preterm births for non-Hispanic Black mothers was double the percentage for White mothers, which can lead to long term negative health and educational outcomes for children. In addition, the percentage of preterm births was nearly three times higher for women who did not receive prenatal care compared to women who entered prenatal care in their 1st trimester. During 2015-2016, 52 percent of non-Hispanic black mothers entered prenatal care in the 1st trimester compared to 86 percent of non-Hispanic white mothers and 64 percent of Hispanic mothers, highlighting the impact that poor access to prenatal care can have on infant health.

The Healthy Start program is working and has impacted families and communities throughout the United States. In 2015, Healthy Start reduced infant mortality rates among Healthy Start program participants to 5.2 infant deaths per 1,000 live births – lower than the national rate of 5.96. That same year, 68.3 percent of Healthy Start participants initiated prenatal care during the first trimester. Healthy Start also helps remove barriers to accessing health care. It helps eligible women and children enroll in Medicaid or private insurance, and in 2014 over 92 percent of program participants had some form of health insurance, further increasing their access to critical health services.

Despite its success, this program has not been reauthorized since 2013. The Healthy Start Reauthorization Act of 2019 would not only reauthorize this essential infant and maternal health program for another five years, it would also provide a necessary increase in the authorized appropriations level.

This bill also makes key changes and updates to the program, including explicit consideration of social determinants of health. The AAP wholeheartedly supports this update to the program, as we know that negative environmental influences can lead to adverse health outcomes in birth, childhood, and across the lifespan, negatively affecting physical health, socioemotional development, and educational achievement. We know that poverty, a key determinant of health, has a profound effect on indicators such as birth weight and infant mortality.[9] Child poverty also influences genomic function and brain development, mediated by exposure to toxic stress,[10] a condition characterized by "excessive or prolonged activation of the physiologic stress response systems in the absence of the buffering protection afforded by stable, responsive relationships."[11] These impacts on child brain development begin prenatally. As such, it is crucial that Healthy Start formally recognizes these challenges and supports providers in addressing them as it continues to deliver services

This reauthorization of Healthy Start also encourages grant applicants to collaborate with local communities in the development of their projects. As a pediatrician who works with multi-disciplinary partners in the local community, including parent run organizations, I cannot emphasize enough how important it is to collaborate with local organizations and leaders when developing programs and initiatives that will provide services in a local community. This is crucial in the development of quality and responsive programs and in gaining buy-in from participating providers and, most especially, those who will receive services.

For all these reasons, the AAP supports the reauthorization of the Healthy Start program. It is a much-needed program that works in reducing preterm birth, infant mortality, and maternal mortality. If we want to continue to improve the lives of mothers and babies across the country, Congress must reauthorize Healthy Start immediately.

Thank you for the opportunity to be here today. We look forward to working with the subcommittee to quickly advance these two important bills for child health.

[1] See https://www.cdc.gov/sids/data.htm#suid-chart.
[2] https://www.cdc.gov/sids/data.htm#suid-chart.
[3] Kamal R, Hudman J, and McDermott D. "What do we know about infant mortality in the U.S. and comparable countries?" *Peterson Center on Healthcare and the Kaiser Family Foundation Health System Tracker*. Published on October 18, 2019. Accessed on December 30, 2019. Accessed from: https://www.healthsystemtracker.org/chart-collection/infant-mortality-u-s-compare-countries/#item-.
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[6] Ely DM, Driscoll AK.
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[10] Boyle CA, Boulet S, Schieve LA, et al. *Trends in the prevalence of developmental disabilities in US children, 1997-2008. Pediatrics. 2011;127(6):1034–1042pmid:21606152*
[11] Garner AS, Shonkoff JP; Committee on Psychosocial Aspects of Child and Family Health; Committee on Early Childhood, Adoption, and Dependent Care; Section on Developmental and Behavioral Pediatrics. *Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health. Pediatrics. 2012;129(1). www.pediatrics.org/cgi/content/full/129/1/e224pmid:22201148*