room doors. That was the last time he saw her alive. Photo credit: Rose Hoban.

December 10, 2019 by Anne Blythe (https://www.northcarolinahealthnews.org/author/anneblythe/)

*North Carolina looks for ways to close prominent racial disparity gaps in infant mortality and maternal health rates.*

**By Anne Blythe**

The harrowing anecdotes have become all too familiar.


Superstar Beyonce revealed particulars from her exceedingly difficult pregnancy and near-death experience during the emergency C-section birth of her twins (https://www.vogue.com/article/beyonce-september-issue-2018) in the same magazine eight months after Williams.

Kira Dixon Johnson, a mother of two who died hours after the birth of her youngest son from complications of a scheduled C-section, is not here to tell her story.

related: NC's maternal mortality strategy relies on ‘medical homes’ (https://www.northcarolinahealthnews.org/2017/12/26/21699/)

Her widower, Charles Johnson, has made it his mission to make sure others hear of his family's heartbreaking ordeal.
Hours ticked by after the birth as they tried to get their health care providers at Cedars-Sinai Medical Center in Los Angeles to pay attention to internal bleeding. Johnson, son of TV judge Glenda Hatchett, stopped in North Carolina earlier this fall to help foster a broader conversation about the life-threatening complications experienced by black women and their infants during pregnancy, childbirth and recovery.

‘Black eye’ for North Carolina

The racial disparities are more pronounced in North Carolina than much of the country, both for maternal health and infant mortality rates.

Those data and how to drive down the numbers were part of a three-hour discussion on Friday when the Early Childhood Advisory Council (https://governor.nc.gov/issues/education/early-childhood-advisory-council) met in Raleigh.

Even though North Carolina has decreased the rate of infant deaths by 47 percent since the advisory council was formed in 1991, African American births result in infant mortality at a rate 2.5 times the rate of white births.

Mandy Cohen, the North Carolina secretary of health (https://www.northcarolinahealthnews.org/2017/03/30/gov-coopers-hhs-pick-passes-first-confirmation-hurdle/), lauded the work that has gone into lowering the overall numbers, but described the racial disparities as a continued “black eye” for North Carolina.

Keisha Bentley-Edwards, a developmental psychologist at the Duke University medical school (https://medicine.duke.edu/faculty/keisha-leanne-bentley-edwards-phd), told the council that any discussion “requires you to talk very concretely about race.”
In North Carolina, she said, there is an over-representation of African Americans living in poverty and the health disadvantages that come with it. But that alone, Bentley-Edwards said, does not explain the maternal health and infant mortality disparity.

Nor does the higher rate of obesity among African American women, she added. When comparing the infant mortality and maternal health complications to white women with the same obesity issues, the rates remain higher for African American women.

The last time the state compiled multi-year data in 2013, researchers found that over a 13-year period, African American women were three times more likely to die as a “result from complications of the pregnancy itself, interventions elected or required because of the pregnancy, or from the chain of events initiated by the complications or interventions, or from a disease which was obviously aggravated by the physiologic effects of pregnancy,” as the Centers for Disease Control and Prevention defines maternal mortality.

“We see these numbers when you look at women who haven’t graduated high school to those who have graduated from college and have a Ph.D. and more,” Bentley-Edwards said.

“It’s not me being a black woman that’s a risk factor, it’s not my skin color, it’s society,” Bentley-Edwards added, underscoring her pitch that any leaps in progress must take into account the ill effects of institutional racism that have plagued this country and state for centuries.

#ListenToBlackWomen

The story of what happened to Williams after she gave birth to her daughter Alexis Olympia Ohanian Jr. on Sept. 1, 2017, played into the advisory council discussion.
Williams, who has won more tennis singles titles than any other player, male or female, in the Open Era, has a history with blood clots in her legs and lungs. Clots in the lungs, in particular, can turn deadly quickly.

On Sept. 2, the day after her C-section, Williams had trouble breathing and alerted a nurse to what she feared was a potentially fatal clot in her lungs. She asked for a blood thinner and a CT scan, according to the Vogue report, but the nurse conjectured that perhaps she was befuddled by pain medication. A physician performed an ultrasound on her legs and found nothing.

Williams continued to advocate for herself against the pushback. A CT scan eventually showed just what she posited, small blood clots scattered throughout her lungs.

She was hooked up quickly to a heparin drip and after several months of tough recovery, has returned to the tennis court with her elite play.
“She makes money from her body,” Bentley-Edwards said. “If folks don’t take that seriously, how am I supposed to be taken seriously.”

Too often, Bentley-Edwards said, black women’s self-advocacy is interpreted as ignorant, histrionic or disrespectful, interpretations with roots in the systems of slavery.

“We have to recognize that black women are an expert on their own bodies,” she said, suggesting a social media hashtag campaign #ListenToBlackWomen.

‘There is no silver bullet’

Cohen, the state health secretary for nearly two years, and commission members say expanding Medicaid eligibility to as many as 550,000 low-income adults who could qualify for the federal assistance could help close the disparity gap.

Pregnant women who qualify for Medicaid are covered for all care related to the pregnancy, delivery and any complications that may occur during pregnancy and up to 60 days postpartum, according to the American Pregnancy Association. But that’s where it ends. Investing in a woman’s health before she becomes pregnant and afterward are important goals toward closing the gap, health care advocates say.

“The focus must be on infant mortality and maternal health because you cannot have one without the other,” said Belinda Pettiford, head of the Women’s Health Branch at the state Department of Health and Human Services.

Efforts to lower the infant mortality rate are deeply intertwined with maternal health care needs, the commission members said, citing preterm birth and low birth weights as great risk factors for childhood death in the first year.

But Medicaid expansion has been tied up for years. This year, Gov. Roy Cooper, a Democrat, and Republican lawmakers at the General Assembly helm have been locked in a budget stalemate over his push to expand Medicaid and their resistance.
Adam Searing, a research professor at the Georgetown University Center for Children and Families (https://ccf.georgetown.edu/author/adam-searing/), pointed out that Medicaid expansion states have reduced the percentage of uninsured women of childbearing age, as well as provided better access to prenatal vitamins that can help stave off problems at and after birth.

In North Carolina, 16 percent of women of childbearing age are uninsured, Searing’s report states. And Medicaid expansion in Ohio, Searing pointed out, led to a nearly 12 percentage-point increase in Medicaid enrollment for first-time mothers before they became pregnant.

But with Medicaid expansion continuing to be a political flashpoint, Cohen challenged Searing to offer ideas beyond Medicaid expansion to help close the disparity gap.

He responded by suggesting a push for guaranteed 12-month post-partum coverage for each woman on Medicaid, a change that would require a waiver or federal legislation. He highlighted programs such as the one at the University of North Carolina at Chapel Hill and other community care programs that focus on the “fourth trimester.”

Searing also suggested that a data collection program be set up to compile complaints to managed care companies, that often oversee care. Managed care companies will also be running the state’s Medicaid program once the program transforms in the near future (https://www.northcarolinahealthnews.org/2019/12/05/medicaid-transformation-will-happen-dhhs-says/).


Among the suggestions were bias recognition training programs for health care workers, campaigns against obesity, smoking and toxic stress, as well as building trust in communities that have long been marginalized.

“I think you have to take a multi-pronged approach,” Bentley-Edwards told commission members. “There is no silver bullet.”

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Anne Blythe, a reporter in North Carolina for more than three decades, writes about oral health care for North Carolina Health News.