The News&Observer

POLITICS & GOVERNMENT

Urban or rural, black lives in NC are being cut short almost before they begin

Laura Miles holds her oldest living son, Dasan, 7, in the family's Durham backyard Oct. 5, 2019. Miles first child, Kingston, was born at 23 weeks with underdeveloped lungs and died in a day.

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BY LYNN BONNER

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North Carolina has one of the worst records in the nation for the deaths of children a year or younger. The rate of black babies' deaths is a big reason.

CHJ

In partnership with the Center for Health Journalism

Our articles about the higher death rate for black babies and what North Carolina can do about it were produced as a project for the USC Annenberg Center for Health Journalism's National Fellowship.

AHOSKIE

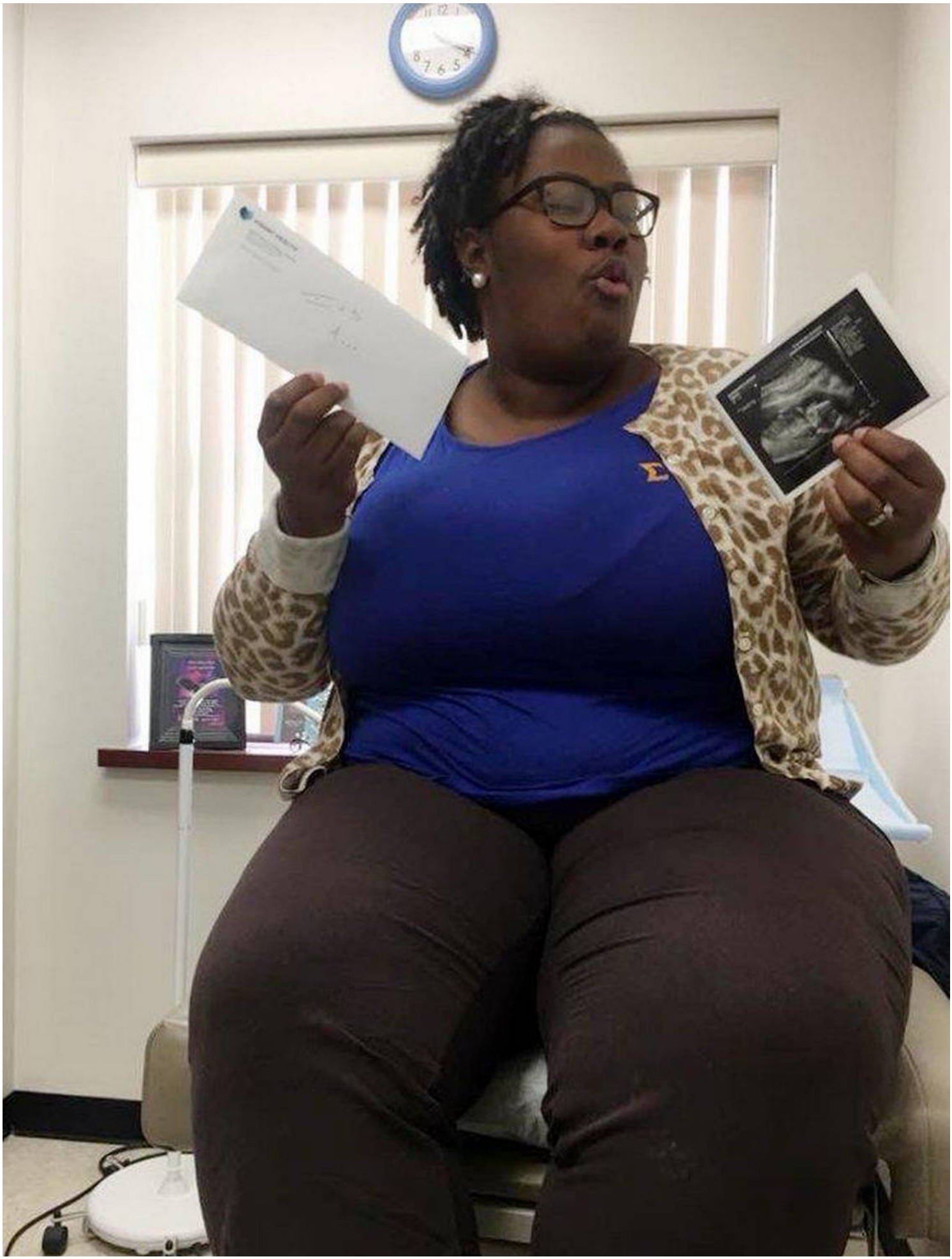
At Christmas, Renee Schoolfield hangs ornaments decorated with her children's names. On Halloween, she wonders what costumes she would have put on her son and daughter — if they had lived.

Reminders of the two children Schoolfield lost nine months apart are throughout her house and stored as photos and videos on her cellphone. Both children were born prematurely and lived less than a day.

Her daughter, Rayna, who lived three hours, and her son Dallas, who lived just an hour, were two of the more than 300 black babies who died in North Carolina in 2018. Together, they are part of a sad fact about the risk of being born black in North Carolina and the United States: Black babies are more than twice as likely to die before their first birthdays than white babies.

Schoolfield was 20 weeks pregnant when she went into early labor and gave birth in February 2018 to Rayna.

"We just held her until she passed away," said Schoolfield.



Renee Schoolfield reacts to finding out the gender of her first baby, Rayna, in January 2018. Courtesy of Renee Schoolfield *COURTESY OF RENEE SCHOOLFIELD*

Schoolfield, 33, grew up in Hertford County. Except for attending Elizabeth City State University and a few years living in Atlanta, she has lived in this rural county close to the Virginia border, about 120 miles northeast of Raleigh.

Her cellphone video of a gender-reveal party in a park shows a gathering of family and friends celebrating the anticipated arrival of a baby girl.

Schoolfield said she had one instance of bleeding that sent her to the emergency room very early in her pregnancy, and responded to her doctor's worry about her weight by dropping 30 pounds.

Schoolfield weathered a depression over her daughter's death. By summer that year she was pregnant with a boy.

The second gender-reveal party was just Schoolfield and her fiance Domonique Moore in a Chinese restaurant opening an envelope. They had plans for another big party, but couldn't wait to find out whether they were having a son or daughter. She called it their "secret gender reveal."

With the second pregnancy, Schoolfield, a community health worker, started taking progesterone injections at 16 weeks to ward off early labor. It happened again anyway. Dallas was born at 22 weeks.

"I did everything I was supposed to do. Got my injections. Took my prenatal vitamins," Schoolfield said. "We were thinking that everything was going to be better, but it turned out the same."

Prematurity and birth defects are the top two reasons babies die before they turn a year old.

North Carolina continues to have one of the worst records in the nation for the deaths of babies a year or younger. The rate of black babies' deaths is a big reason.

Statewide, the gap between black and white infant deaths was wider in 2018 than it was in 1999. The state has had to acknowledge that it won't meet its goals for reducing that gap by this year.

"It's an atrocity and we need to address it," Dr. Mandy Cohen, head of the state Department of Health and Human Services, said of the racial gap at an October maternal and infant health summit convened by the NC Medical Society and its foundation.

"Rayna and Dallas are buried at my mom's house on our family land, I got these flags made as burial markers. My mom does an awesome job with keeping the yard looking beautiful for them," says Renee Schoolfield who lost both of her children shortly after they were born. Courtesy of Renee Schoolfield *COURTESY OF RENEE SCHOOLFIELD*

Grieving the deaths of her children, Schoolfield found a well of support among family, friends and coworkers. And in writing about her experiences on social media, she found that other women from the Ahoskie area had stories of the deaths of their own babies.

"A lot of our Facebook friends were messaging us that they went through the same thing," she said. "A lot of people in this area lost children."

Hertford County, where Ahoskie is the biggest town, makes up a small crescent of three counties in northeastern North Carolina that includes Bertie and Washington counties that from 2014-2018

had the highest infant mortality rates in the state.

Schoolfield and Moore said they know why infant deaths are more common in their area.

"In rural areas, there's not really wide access to health care," she said.

"Some people can't afford to go farther. They don't have the transportation to go to all these appointments."

Economic opportunity in the region is lagging, Moore said, and good-paying jobs are scarce.

"Lack of resources, knowledge, pay, everything," he said.

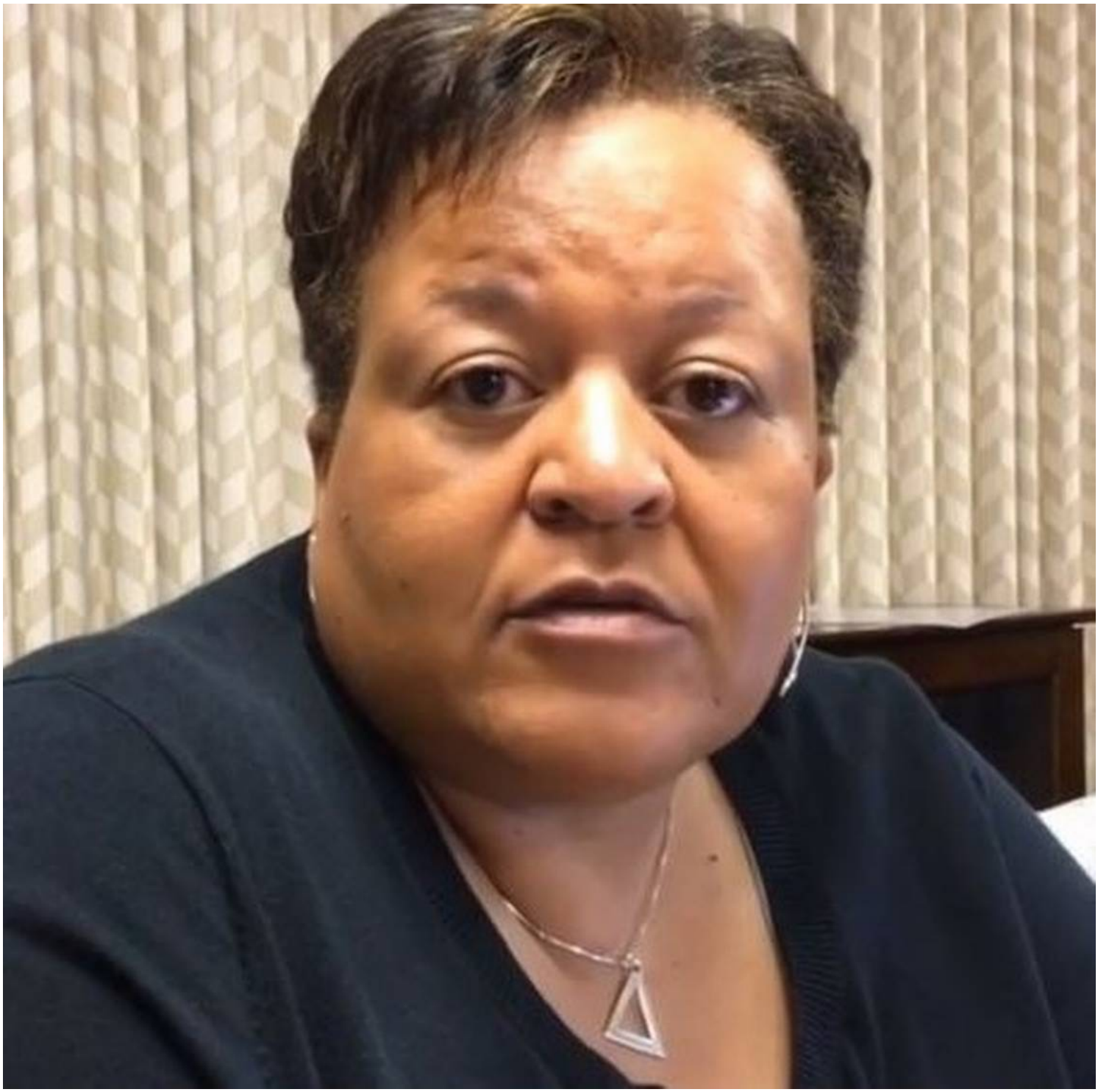
NO CONSISTENT PROGRESS

North Carolina has tried for years to try to narrow the gap between black and white infant deaths and keep more black babies alive.

In 2011, the state published a plan called Healthy North Carolina 2020 that had as one of its goals narrowing the racial gap to lower than 2 — specifically to 1.92 — by 2020. It was soon clear that the state wasn't going to reach that goal. In some years, the racial gap in infant deaths grew. In 2010, the ratio was 2.4. In 2016, it was 2.68.

Last year, North Carolina essentially reset the clock, committing to reach the 1.92 disparity ratio by 2025 as part of its Early Childhood Action Plan.

In 2018, the death rate for all babies dropped to its lowest level in decades, and the difference between black and white death rates narrowed slightly. But black babies were 2.44 times more likely to die in 2018 than white infants, a wider gap than 2.33 times in 1999. Information for 2019 is not yet available.



Belinda Pettiford is head of the women's health branch at the North Carolina Department of Health and Human Services. *NEWS & OBSERVER FILE PHOTO*

The racial difference in baby deaths is a national problem that states, local governments, neighborhoods, and nonprofits say they are trying to solve.

"It's been our greatest challenge," said Belinda Pettiford, head of the women's health branch at the state Department of Health and Human Services. "Even with North Carolina's infant mortality rate at its lowest in the state's history, we still struggle with that disparity ratio. We have

realized that until we address the disparity ratio our overall infant mortality rate won't get a lot better."

State efforts to reduce the racial gap in baby deaths focus largely on low-income women. Poverty has a role in how often women see doctors, the food they can afford, and where they live.

Still, some black infants who don't survive are born into families who have good insurance and doctors nearby.

THE ROLE OF RACISM

Black babies die at higher rates than white babies no matter their mothers' education level or age. In fact, black babies whose mothers have graduate or professional degrees die at higher rates than white children born to mothers who didn't finish high school, said Keisha Bentley-Edwards, an assistant professor at Duke University's School of Medicine who studies health equity.

Death rates drop for infants born to white women 20 and older, and don't increase until the women are in their 40s. Infant mortality rates are higher for babies born to black mothers of all ages, and they don't change much as women get older.

"The risk factors for black women are riskier," Bentley-Edwards said, "and the protective factors are not as protective."

Keisha Benley-Edwards *DUKE UNIVERSITY*

A researcher based at the University of Michigan, Arline Geronimus, theorizes that chronic stress from racism and historic discrimination causes health problems, including preterm births, in black Americans. She calls this theory "weathering."

Research on how the body responds to constant stress is getting a lot of attention, Bentley-Edwards said, and doctors should ask expectant mothers about toxic stress, including stress at work.

Efforts to improve infant mortality rates focused on low-income women and children, but did not specifically consider the effects of structural racism, Bentley-Edwards said. As a result, infant mortality rates dropped, but the racial gap is largely unchanged.

"We know that what we've been doing hasn't worked, so it's time to be more innovative," she said.

State money, federal and foundation grants, peer education programs at universities, church-based efforts and programs based at local health departments are all aimed at trying to save more black babies' lives. In 2011, Community Care of North Carolina, the Medicaid management organization in North Carolina, started a program called Pregnancy Medical Home that helps at-risk pregnant women get to doctors' appointments, to pharmacies, or food.

Narrowing the racial gap is one of the priorities for the state Department of Health and Human Services, which has a bundle of strategies aimed at improving expectant mothers' well-being and the health of young children. Part of that effort aims to reduce the influence of implicit bias, unconscious beliefs and stereotypes that affect behavior.

Expectant mothers need to be comfortable with providers and treated equitably, Pettiford said. Good housing, food, safe homes and communities are also key.

"We spend a lot of time focusing on women themselves," she said. "I think we also have to look at some of the systems women are engaged in."

Pettiford said she's seen providers label women "non-compliant" when they fail to show up for appointments without medical offices considering the obstacles patients may face getting to the doctor.

"What were the barriers that kept her from getting to her appointment on time?" she said. "Is she working somewhere where she doesn't have paid parental leave" or doesn't have paid vacation or sick time?

EASTERN NORTH CAROLINA LAGS

The eastern part of the state — counties from Northampton in the north to Onslow in the south and Halifax, Nash, Wilson, Wayne and Duplin on the western border — has wrestled for years with higher infant death rates than the state average.

Dr. James deVente, medical director of obstetrics at Vidant Medical Center and an associate professor at East Carolina University's Brody School of Medicine, noted an accomplishment when, in 2017, the region matched the state average of 7.1 infant deaths for every 1,000 births. By 2018, though, the rate was higher again.

DeVente and Angela Still, a registered nurse and administrator for women's services at Vidant Medical Center, have been working for years to reduce baby deaths in Eastern North Carolina.

Since 2012, they've led a program to help smaller hospitals in the region better prepare for expectant mothers and new babies with serious medical conditions. Vidant Health covers the cost of the outreach program.

The outreach program also helps figure out what equipment those hospitals need and offers instruction on topics such as fetal monitoring.

The program led to arrangements that allow small hospitals to have ready access to surfactants, drugs that help premature babies with underdeveloped lungs breathe.

DeVente said small hospitals did not keep the drug on hand because it is expensive and has a short shelf-life. In a small hospital that sees relatively few patients, a hospital might have to throw out the expensive drugs. Now, the small hospitals and Vidant Medical Center in Greenville have an arrangement that allows the small hospitals to keep the drug in stock without worrying about waste.

The hospital also offers women the option of having contraceptive devices inserted before they leave the hospital after giving birth to reduce unintended pregnancies and extend the time between pregnancies. Medicaid covers the cost of the devices, Vidant Health spokesman Jason Lowry said in an email. Having babies too close together is associated with premature births and low-birth weights.

"It's a contributor to infant mortality," Still said. Long-acting, reversible contraception "will increase the amount of time when she has another baby." The decision to use the device is up to the women, Still said, and it can be removed.

The gap between white and black infant death rates has not narrowed in the region, and deVente and Still aren't sure why.

"I think that's like the holy grail of obstetrics right now," deVente said. "I'm not sure anyone knows the key to it."

In 2018, state data shows that no white infants from Pitt County died before age 1, while 11 black infants from Pitt County died before their first birthdays.

URBAN COUNTIES ARE WORSE THAN THE STATE AVERAGE

The mortality gap is not exclusive to rural and low-wealth counties. Black babies die at higher rates in the state's wealthiest, metropolitan counties. From 2014-2018, black babies from Wake County were nearly 3.8 times more likely to die as white babies from the county. Durham had a gap of 3.5 over the same years.

Durham resident Laura Miles is much more selective about the doctors she sees after her first child, Kingston, died in 2009 shortly after his birth. The experience convinced her that first-time mothers need support and advice while pregnant and interacting with doctors.

Miles, who grew up in the Bronx and moved to Durham to attend N.C. Central University, has a condition that she thought would prevent her from getting pregnant.

"I didn't even think it was possible," she said.

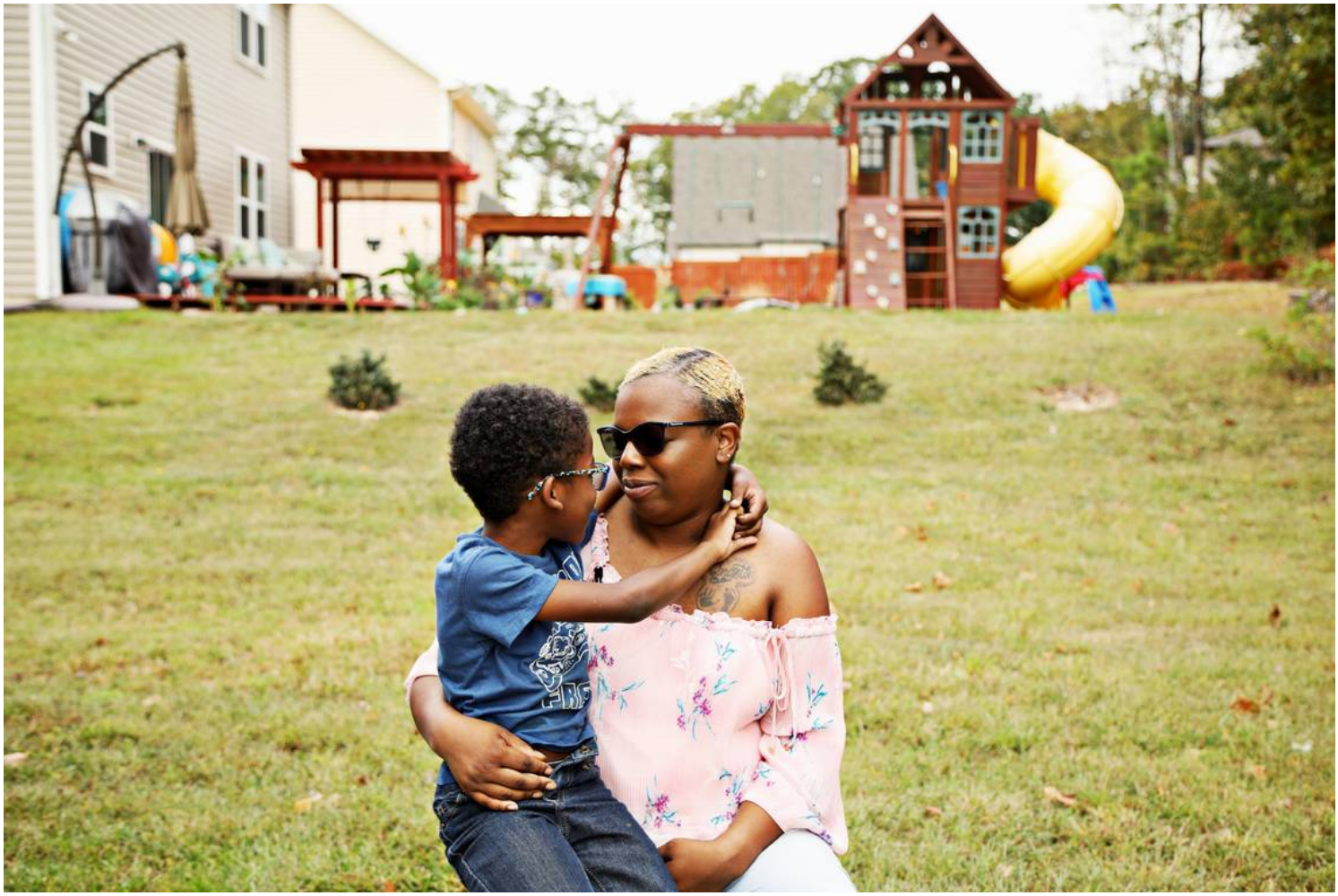
Several months pregnant with Kingston, she felt pains and went to her doctor.

"I kept telling them, I have cramps here, I have pain here," Miles said. "The response was, 'Well, pregnancy hurts.' And they really didn't address the fact that I was in pain."

Miles worried that she wasn't being taken seriously. Her husband convinced her to switch doctors.

Miles went into early labor, and Kingston was born at 23 weeks with underdeveloped lungs. He died in a day.

"Kingston was an accident," she said, "but he was a miracle because I was told I had a 30% chance of ever having children. I put it into my head that I am actively going to try to get pregnant."

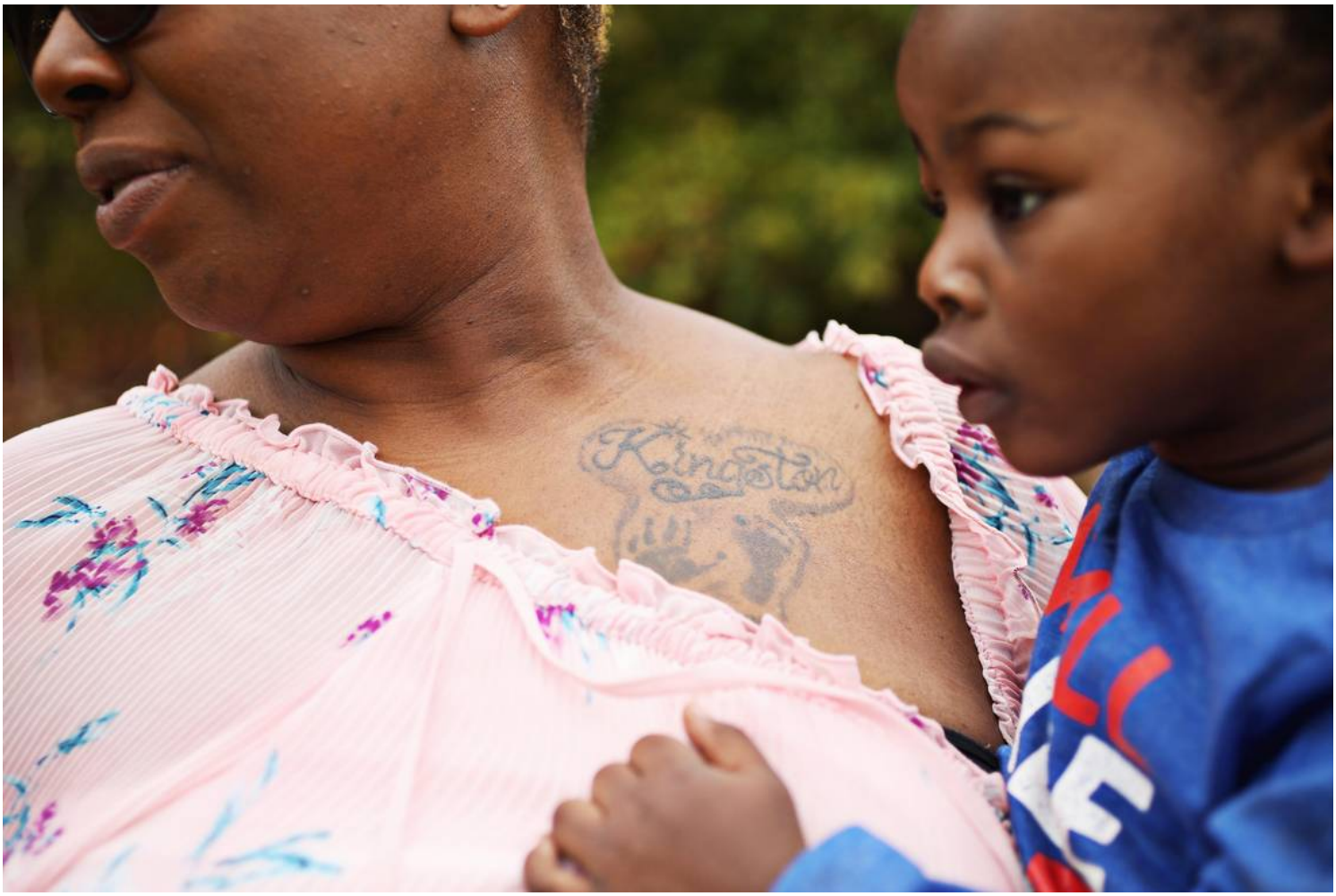


Laura Miles holds her oldest living son, Dasan, 7, in the family's Durham backyard on Oct. 5, 2019. Juli Leonard *JLEONARD@NEWSOBSERVER.COM*

It took more than two years for Miles to get pregnant again. And she started feeling the same pains she felt with Kingston. Her doctor immediately ordered an ultrasound, she said. She had a surgical procedure to prevent preterm labor. Dasan — the son Miles calls a "foodie" who grew to love curry goat, rice and peas, and oxtails — was born about 9 1/2 weeks later.

He and his two younger brothers ran around the house one Saturday afternoon as Miles worked to get them organized for a trip to the grocery store.

"If my first provider was as proactive, maybe those steps could have been taken," she said. "Maybe Kingston could have been here. If they had dug a little deeper and just addressed the concern I had instead of just writing it off."



Durham resident Laura Miles had her first child, Kingston's hand and foot prints tattooed on her chest shortly after he died in 2009. Kingston, who only lived briefly after birth, would be turning 11 this summer. Juli Leonard *JLEONARD@NEWSOBSERVER.COM*

POSSIBLE SOLUTIONS

Democratic Gov. Roy Cooper's administration pushed to expand Medicaid government health insurance to more uninsured adults in the last year. Research has shown that states that expanded Medicaid saw bigger drops in black infant death rates.

Medicaid pays for more than half the births in the state.

The state House held hearings on a proposal to extend insurance to adults who meet income guidelines, work, and pay premiums. Republicans in the state Senate have refused to consider expanding Medicaid, saying it would cost too much.

A study from 2018 found that black infant mortality rates improved more in states that expanded Medicaid compared to states that didn't expand the health insurance program to more low-income adults.

Dr. Elizabeth Tilson, state health director and chief medical officer at DHHS, said Medicaid expansion would be an important step.

Communities must also look at how families are supported during and after pregnancy, Tilson said, and both women and men need to be engaged in planning for pregnancies and children.

"It's not just one thing," Tilson said. "It has to be a combination of things across the life course."

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