

After initiative, progress in fight for lives of babies

Five years later, fewer babies are dying in Leon County, but racial disparities remain

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Leon County's infant death rate is down, but preterm births remain an issue. The tiniest babies spend time at Tallahassee Memorial Healthcare's Neonatal Intensive Care Unit, which serves families within 120 miles. In one quiet room last month, volunteer 'cuddler' Jeannie Causseaux prepares to bathe a premature baby. / Glenn Beil/Democrat

In March 2008, Leon County politicians, health care experts, social service workers and citizens came together for a day-long workshop focused on reducing infant deaths and eliminating a stubborn racial disparity that saw black babies dying at a rate of nearly four times that of white babies.

Work groups were formed. More meetings followed. Goals were set. In time, interest in the issue among the general public faded, but those on the front lines kept pushing, prodded by year-long reporting and editorial advocacy in the Tallahassee Democrat.

"People did it kind of quietly," said Ann Davis, executive director of the Capital Area Healthy Start Coalition. "We just got in the trenches and worked."

Five years later, the county's infant mortality rate —a key indicator of a community's health —is at a near all-time low. Not since 1996 have fewer infants died in Leon County. For three of the last five years, the number of county babies who died before their first birthday dropped below the state average for both blacks and whites. That hadn't happened since the mid-1990s, either.

Former state epidemiologist Dr. Bill Sappenfield said overall, Leon County's recent infant mortality statistics show a "significant downward trend."

"You have some good patterns there," said Sappenfield, now a professor at the University of South Florida, chair of its Department of Community and Public Health and director of the Chiles Center for Healthy Mothers and Babies. "It looks like over time, Leon County has closed the disparity with the rest of Florida. There has been progress."

Disparity remains

The disparity between the races, however, has not gone away. State Department of Health statistics from 2011, the most recent year available, showed black infants in Leon County died at a rate of 9.5 per 1,000 live births compared to a rate of 3.1 for whites. Those rates reflect the death of 12 black infants and 5 white infants. While the number for both races hasn't been lower in 15 years, black babies are still three times more likely to die.

"If the (downward) trend is statistically significant, that's good," said Dr. Edward Holifield, whose tenacity helped to bring the issue of black infant mortality to the community's attention. "But compared to the need, it's a drop in the bucket —unless you are going to say it's OK for blacks to die at three times the rate of whites."

About this series:

“Healthy Babies” is a month-long effort by the Tallahassee Democrat intended to enlighten the community about efforts to reduce infant deaths and promote positive birth outcomes. Every Wednesday of the month will feature in-depth articles with an accompanying video at Tallahassee.com. Additionally, video vignettes featuring survivors of preterm birth will be posted each Wednesday, Thursday and Sunday. Tips for having healthy babies will be published in TLH Local four days a week. On Sunday, April 30, the Democrat will post a long-form video documentary summing up the series. Coming up in the Tallahassee Democrat and Tallahassee.com:

- April 10: Who is doing the work —and what’s working?
- April 17: Having a healthy baby —what does it take?
- April 24: Where to go from here?

Free screenings

Whole Child Leon and partnering agencies are hosting a free developmental screening for babies, toddler and preschoolers. Experts will screen children for vision, hearing, speech, behavior, growth and other developmental issues from 8:30 a.m. to 12:30 p.m on Friday at Children’s Medical Services, 2390 Phillips Road. The screenings are free, but do require an appointment. Make a reservation by calling 850-487-2630, extension 0.

VIDEO

For a look inside TMH’s Neonatal Intensive Care Unit, check Tallahassee.com/NICU.

Go to

www.Tallahassee.com/healthybabybonfanti for a prematurity survival story featuring the daughter of Mark and Joanna Bonfanti, Lucy Elizabeth Bonfanti.

associate dean at Florida State’s College of Medicine, said the attention surrounding the Year of the Healthy Infant may have been a catalyst.

“I would like to think that got the word out to more of the women who were high-risk,” said Littles, who was active in the effort. “It really is a multifaceted problem. ... That’s why we have to keep working on it.”

Davis, whose Healthy Start Coalition is charged by the state to help reduce infant mortality and improve birth outcomes, agrees that greater awareness helped to turn the corner.

“It’s been a concerted effort on behalf of the whole community to get where we are today,” she said. “We had this huge community awareness, then we came together to work on ways we could make a difference. We had different parts of the community step up and do their piece.”

The 2008 Year of the Healthy Infant effort, initiated by the now defunct Leon County Healthcare Advisory Board, set a series of ambitious goals, top among them, to eliminate the county’s infant mortality racial disparity by 2018. An intermediate goal to reduce the black infant death rate to less than 10 per 1,000 was reached in 2009, five years before its target date.

But a year later, in 2010, the county saw a spike in black infant deaths that caused the death rate to skyrocket to more than 18 per 1,000 —six times the death rate of white infants that year. The high death toll was considered by experts a sad anomaly, and a year later, the black infant death rate was back down to around 9 deaths per 1,000 births, a vast improvement over five years ago. The drop fueled the county’s overall low infant death rate of 5.9 in 2011. The state average for the year was 6.4 infant deaths per 1,000 births. While advocates today are pleased by the apparent headway, they recognize there is a long way to go to eliminate the racial disparity in birth outcomes.

“Have we seen an improvement? Yes. Is it better than it was? Of course,” said Angel Trejo, a retired Department of Children and Families district administrator who currently chairs the Whole Child Leon Steering Committee and is active with nonprofits trying to reduce infant mortality and improve the lives of young children. “Can we do better? Hell yes.”

A 'concerted effort'

No one knows exactly what is driving the reduction in infant deaths. Sappenfield noted a “clear pattern of improvement” in the death rates of infants less than a month old, but there is no conclusive evidence that a certain intervention or effort is behind the positive change.

Experts suspect it likely is a combination of things —from increased education and access to information to better medicine reaching more moms. Dr. Alma Littles, senior

Groups including Whole Child Leon, Healthy Start, Brehon Family Services, March of Dimes, the Leon County Health Department, the state Department of Health, Tallahassee Memorial Healthcare, Florida A&M and FSU's College of Medicine, community health care clinics as well as advocates have remained focused on the issue.

"We are gradually getting to the point where people realize no one program solves this issue," said Ed Feaver, a member and past chair of Whole Child Leon's Steering Committee. "There are too many interrelated and interlocking issues to deal with."

Fighting a 'hydra'

The primary causes of infant death are birth defects, low birth weight, prematurity, maternal or fetal complications and unexplained sudden death, such as Sudden Infant Death Syndrome. But underlying those immediate causes are other influencing factors, such as a woman's health before pregnancy, sleep habits and social issues such as education, poverty, access to health care and personal stress.

"It's like grappling with a hydra," said Dr. Lisa Jernigan, a primary care physician who treats pregnant moms in surrounding counties and a faculty member in TMH's Family Medicine Residency Program.

For reasons not fully understood, black women are at even greater risk of losing a baby than white women. State health statistics show on average, from 2009-2011 in Leon County, black women were more than twice as likely to have a low-birth weight infant. During the same period, about 16 percent of black babies were born preterm compared to about 11 percent for whites.

Black mothers also suffer more from chronic diseases and see a higher rate of sudden infant death, in part, health officials say, because they are less likely to practice safe sleeping habits and receive late or inadequate prenatal and primary health care.

On average, from 2009 to 2011 more than 30 percent of black moms who gave birth in the county were obese, compared to 18 percent of white moms. The rate of sudden infant deaths was more than three times that for whites.

"It's sad to say, but we are always going to lose babies, it's just going to happen," said Leon County Health Department Administrator Homer Rice. "But we really shouldn't have this gap. I don't know how to prove it, but I really think it has a whole lot to do with the stress in the (black) culture."

A one-day meeting, Rice said, won't change that. It will take small, steady steps over time.

"The community has to address this," he said. "There are only so many of us, and frankly, there are only so many resources."

Trejo said the work can't just be left to "hippie-dippy social-worker types."

"It's good business practice to have a healthy community," he said.

Moving forward

When Davis first joined the fledgling Healthy Start Coalition 20 years ago, she said the prevailing wisdom was that if a pregnant woman could get prenatal care for nine months she would have a healthy baby. Not so anymore.

“Now it’s a woman’s health before she gets pregnant. It’s her mother’s health when she was in-utero,” Davis said. “We really need to refocus our whole effort in womens’ health care to getting people from the youngest age understanding how to take care of themselves and respect their bodies.”

Feaver, a former DCF secretary, said groups need to do a better job collaborating and investing resources in more direct services.

“We don’t have the ability to be flexible enough to address the needs of an individual person,” he said. “What we have is a bunch of program concepts and we try to fit people into them. And that to me is the biggest failure we have in health and human service, period.”

Moreover, Holifield and others say it is time to change the conversation to address the root causes of infant deaths and why blacks suffer disproportionately. In fact, the saber-rattler said he doesn’t even want to talk about infant mortality any more.

“We need to talk about poverty ...we need to talk about racism, we need to talk about all these root causes of social determinants,” he said. “Only when that is done in a comprehensive fashion are we going to make some real progress addressing infant mortality.”