I. Process

In Louisiana, the Department of Health and Hospital's (DHH) Bureau of Family Health (BFH) and Title V Children's Special Health Care Needs (CYSHCN) Programs administer the Maternal and Child Health Block Grant Title V funding for the six identified maternal child health (MCH) population domains. The two programs conducted separate assessments of their target populations, communicating throughout the process and convening with stakeholders after data collection and analysis to identify Louisiana's priority needs.

Both BFH and CYSHCN Programs engaged in data-driven, participatory processes. The goals of BFH were: 1) to identify priority needs through a data-driven process; 2) to engage community constituents and stakeholders in the identification of priority needs, their drivers, and solutions; 3) to produce a living, user-friendly document that will serve as the feedback mechanism for BFH's ongoing assessment; and 4) to create enduring community engagement and BFH accountability to community constituents and partners.

The goal of CYSHCN Programs was to identify priority needs through a data-driven process that produced an in-depth understanding of the needs of CYSHCN and their families. They also wanted to better understand how state-level changes since 2010, like the privatization of Medicaid and the closure of just over 70% of direct-service clinics, had affected families. Their process was to gather and analyze quantitative and qualitative data on CYSHCN and the physicians who serve them, so they could better understand a range of issues related to care of CYSHCN, including medical home/care coordination, transition to adult care, developmental screening, and insurance coverage. CYSHCN Programs also wanted to know more about the practices of physicians as they relate to the care of CYSHCN to identify areas for targeted improvement.

Quantitative and Qualitative Methods and Data

To assess the six population health domains, BFH and CYSHCN Programs gathered and analyzed quantitative and qualitative data. The expertise of The Policy & Research Group (PRG), a research and evaluation firm based in New Orleans, was used to collect data not available through state or national databases.

BFH used quantitative data to assess the areas of greatest need across the State's nine administrative regions; data sources included: Louisiana Vital Records, Hospital Discharge Data, Pregnancy Risk Assessment Monitoring System (PRAMS), STD surveillance data, the National Survey of Children's Health, the Youth Risk Behavior Surveillance System (YRBSS), and the National Immunization Survey (NIS). A BFH epidemiologist analyzed 93 performance and outcome indicators, including all 15 proposed National Performance Measures as well as additional indicators of interest, using a scoring matrix (see Scoring Matrix, Appendix A). These data were used to determine target populations and topics for each focus group (see Sample Regional Data Sheet, Appendix A). A BFH epidemiologist then used the proxy of concentrated disadvantage – an economic index calculated at the census tract level – to identify the

geographic areas of greatest need within each region and the target location for each focus group (see Region 7 map, Appendix A). BFH worked with community partners to recruit focus group participants. PRG analysts conducted nine focus groups with women, men, and adolescents in each of the nine administrative regions; they held a tenth group with women in treatment at an opioid clinic. Focus group protocols allowed participants to identify community needs from their own perspective, but they were also tailored according to the issues and needs identified by BFH data analysis (see Region 7 Focus Group Protocol in Appendix A). A total of 55 individuals participated in focus group discussions. PRG analysts and BFH staff also interviewed 37 stakeholders (see General Interview Protocol and Table of Participating Stakeholders, Appendix A). Focus group findings provide in-depth, exploratory insight into participants' perspectives on community needs and health care, while stakeholder interviews with physicians, non-profit leaders, OPH Regional Medical Directors, and heads of state agencies offer expert knowledge about the needs of MCH populations (see Summary Findings of BFH Focus Groups, Appendix A).

CYSHCN Programs initially assessed the needs of CYSHCN with a review of quantitative findings from the 2014 Annual DD Council Survey, the 2009/2010 National Survey of Children with Special Health Care Needs and the 2011/12 National Survey of Children's Health. For information on physician practices, CSHS conducted a survey of pediatricians and family practitioners. The physician survey instrument consisted of 25 closed-ended questions concerning insurance, care coordination, and services provided to CYSHCN (see Appendix B for Physician Survey Report, including instrument). PRG invited 1,338 physicians to participate in the survey. A total of 315 questionnaires (292 online, 23 paper) were completed and returned for an overall response rate of 23.5%. PRG analyzed the data and provided summary results to CYSHCN Programs. PRG also conducted ten focus groups with a total of 56 caregivers of CYSHCN in five administrative regions. Two groups were conducted in each region to compare the experiences of families primarily served by CSHS clinics versus those who are not; in each region, one group was recruited by Families Helping Families (FHF), a network of non-profit organizations that provide support for families across Louisiana, and the other by CSHS staff. PRG analyzed focus group findings to provide CYSHCN Programs with insight into how a select group of Louisiana families experience caring for CYSHCN (see Appendix B for Focus Group Report, including focus group protocol).

To assess MCH program capacity, BFH leadership examined financial data on programmatic investments for the 93 performance and outcome indicators. BFH then created a list of stakeholders to interview to better understand areas where BFH has little to no capacity, like stable housing support. Finally, BFH talked with stakeholders about programmatic capacity in their areas of expertise and held internal discussions to identify strengths and weaknesses in state capacity. CYSHCN Programs used a SWOT analysis to analyze program capacity.

As noted above, BFH identified partners for collaboration in the qualitative data collection process by mapping BFH partners to areas of concentrated disadvantage. BFH then worked with partners in these areas to recruit participants for focus groups.

CYSHCN Programs and its statewide parent liaisons worked with their regional parent liaisons, local FHF chapters, and a statewide organization, the Family-to-Family Health Information Center (F2FHIC), to recruit participants and coordinate focus groups.

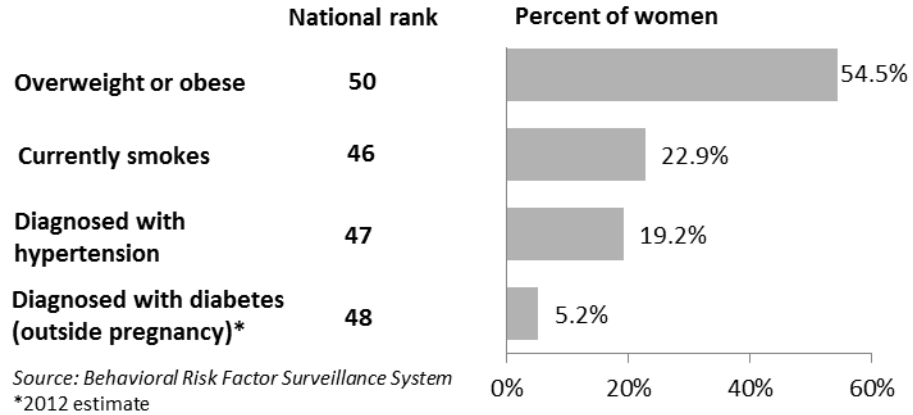
Level and Extent of Stakeholder Involvement
BFH and CYSHCN Programs involved stakeholders throughout the Needs Assessment process. BFH staff and PRG interviewed a total of 37 stakeholders in the data collection phase to solicit their input on the current health status of MCH populations and priority needs. CYSHCN Programs included parent consultants in the development of focus group recruitment strategies and the focus group protocol, as well as in the development of the physician survey instrument.

BFH, CYSHCN Programs, and 12 stakeholders met with AMCHP facilitators to select State Priority Needs and National Performance Measures (NPMs). Quantitative and qualitative data informed the priority-setting process. BFH and CYSHCN Programs leadership then reviewed data and feedback from the Strategic Advisory Group to determine the final seven State Priority Needs and eight NPMs.

II. MCH Population Needs

Women's/Maternal Health
Recent years have seen some improving trends in women's health status in Louisiana. Yet, on a number of indicators, Louisiana ranks last or far below most other states for women's/maternal health status.

Select indicators of health for women ages 18-44, Louisiana, 2013



Source: Behavioral Risk Factor Surveillance System
*2012 estimate

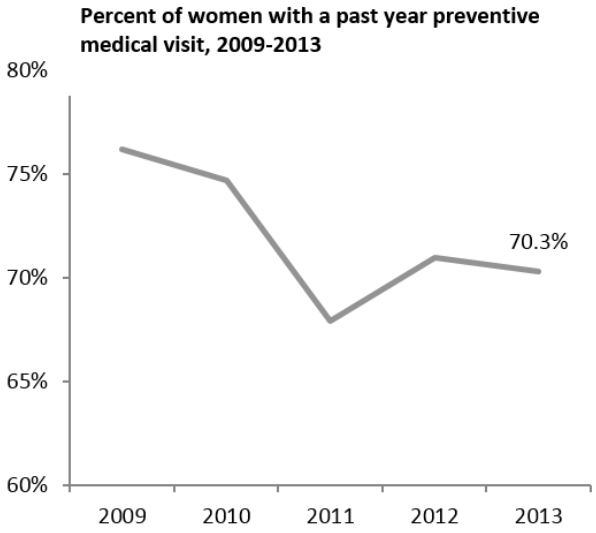
For many women in Louisiana, their underlying health is already compromised before pregnancy. Many of the health conditions listed above ultimately contribute to the state's high rates of preterm birth, low birth weight, and infant and maternal mortality.

BFH will actively engage in ensuring that Louisiana women receive quality preventive care (and preconception care) – both to protect the individual woman's health and also that of her future children. Thus, the Priority Need assigned to this domain is: **Improve**

access to and quality of primary care, reproductive health, and specialty clinical services including care coordination. Success in meeting this need will be measured by **NPM1: Well Woman Visit**.

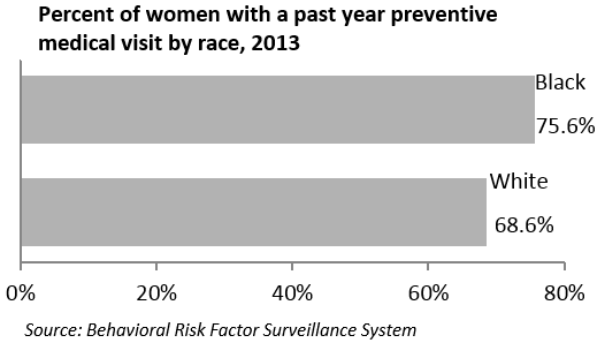
NPM1: Well Woman Visit

The most recent Behavioral Risk Factor Surveillance System (BRFSS) data indicate that 70.3% of women had a well-woman visit within the past year (2013), down from 76.2% in 2009.They also show that while 77.4% of insured women had a preventative care visit, only 52.7% of uninsured women did. Stakeholders confirm that a lack of insurance decreases women's receipt of preventive care.

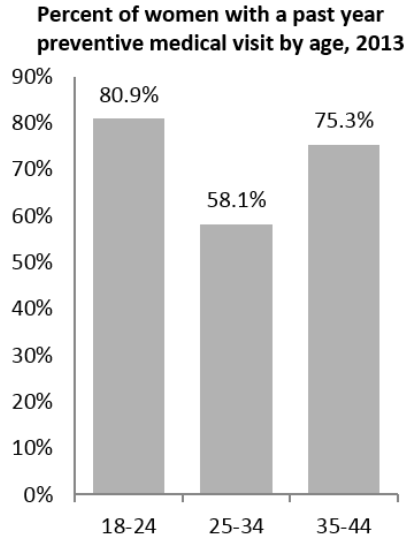


Well Woman Visit Disparities

Black women are more likely to receive regular preventive care than white women and women ages 25-34 – prime childrearing years – are far less likely to receive regular preventive care.



Source: Behavioral Risk Factor Surveillance System



Many of the women who participated in the BFH focus groups said they do not receive regular preventive health care, and stakeholders – including ob/gyn's – agreed that a lack of routine, preventive care is a problem among their low-income patients. One stakeholder said that "*unless you are pregnant . . . there is just not a lot for you within the Medicaid system [in Louisiana] right now*." Stakeholders said that while women may come in for preventive care, follow-up care to treat chronic or other conditions is often not covered by Medicaid and other managed care plans, or it is too expensive for women without insurance.

I had [Medicaid] when I was pregnant . . . I could get everything free.

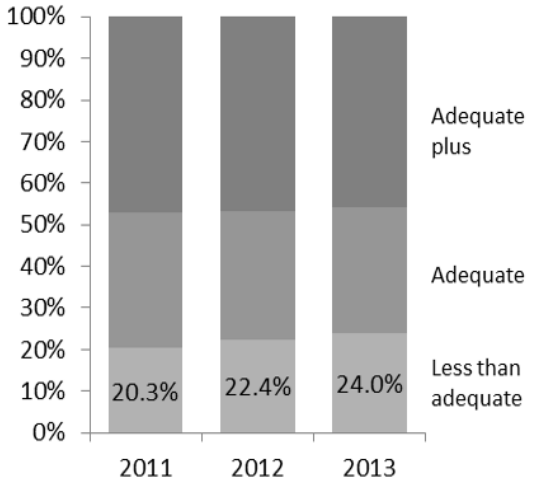
– BFH Focus Group Participant

Our obstetric population is covered. It's not perfect, but it's covered.

– BFH Stakeholder

One doctor said "*funding for imaging, like mammograms, ultrasounds, CAT scans*" is difficult to find for women who cannot pay. She also noted that women who lack a social security card – usually because they are undocumented immigrants – have to pay cash for preventive medical care. For patients like this, she said, "*every point of care is a struggle*."

Percent of Women Receiving Adequate Prenatal Care, 2011-2013



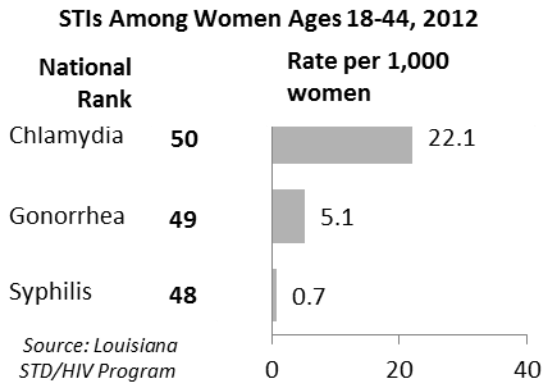
Source: Louisiana Vital Statistics

Adequacy of Prenatal Care

The Kotelchuck Adequacy of Prenatal Care Utilization (APNCU) Index uses month of prenatal care entry and number of prenatal visits for gestational age at delivery to classify a women's prenatal care as inadequate, intermediate, adequate, or adequate plus. While Louisiana does fairly well with respect to the percent of women who achieve at least adequate care, a high proportion of these women belong to the adequate plus group thereby indicating receipt of a higher volume of visits suggesting the need to manage the higher burden of chronic conditions among many Louisiana women.

Stakeholders and focus group participants alike said that as long as women were able to sign up early and easily for Medicaid, they could access good prenatal care. Some stakeholders expressed concern that the wait was sometimes too long for Medicaid coverage to begin, especially for vulnerable groups like the uninsured, women who struggle with substance use disorders, and undocumented immigrants. BFH believes that enrollment in Medicaid prenatal coverage needs to be monitored due to changes in enrollment into coverage through Medicaid and the new MarketPlace, as well as changes in the prenatal care provider landscape.

Women in some regions described a lack of access to gynecological care in their area; they have to travel long distances – even though they often do not have reliable transportation – to see a doctor or get prenatal care. Many women also identified sexually transmitted infections (STIs) as problems in their communities. One woman in a rural Louisiana community said, "*They [STI's] pass around down here like mosquitoes.*"



As noted above, obesity is a significant problem among Louisiana women. Many of the women who participated in focus groups said that while they know what foods constitute a healthy meal, they often cannot afford to buy them. An ob-gyn interviewed for the needs assessment said that her low-income patients often lack access to safe places to exercise and/or lack knowledge about how to exercise.

> *You can't afford [healthy food], so you gotta eat what you can eat.*
>
> -BFH Focus Group Participant
>
> *They don't know what to do . . . you're like "Go out and exercise." "Well, I'm going to get shot. Where am I going to go walk? Where am I going to swim?" So saying that to an inner-city African-American woman, she's like, "Listen, I'm not living in the suburbs.'" So it's hard.*
>
> -BFH Stakeholder

BFH focus group participants acknowledged that depression and substance use disorders are problems in their communities. In 2013, 22% of Louisiana women ages 15-44 were diagnosed with a depressive disorder; 31% reported that their mental health had been good for less than five of the prior 30 days (BRFSS). Focus group participants believe that most people in their communities do not seek help due to shame or embarrassment. Focus group participants and stakeholders also acknowledged the growing problem of substance abuse among Louisiana women, especially pregnant women. The focus group participants with whom we spoke who are in opioid treatment said that people often do not understand addiction and that they lack support networks outside of the treatment center.

> *People that aren't addicts, they don't know because they're, like, 'Oh, it's just mental. You know, you can just stop.' No. No, you can't.*
>
> – BFH Focus Group Participant

BFH is committed to recognizing and understanding the drivers of health concerns and inequities in Louisiana. Many focus group participants described how struggles with resources – finances, employment, housing – undermine their family's ability to achieve

good health. In most focus groups, participants said jobs and financial assistance are inadequate in Louisiana. Government resources, participants often said, do not help families achieve stability. Parents – especially single mothers – also said that finding and keeping a job is difficult, especially given the expense of child care, the quality of which is often seen as inadequate.

> *It's hard here. It's harder in Louisiana.*
> – BFH Focus Group Participant
>
> *They keep you in poverty in order for you to get services.*
> –BFH Focus Group Participant

Focus group participants said that while some fathers do remain involved in their children's lives, others do not, and they usually attributed the lack of father involvement to incarceration or unemployment. Though some mothers complained about the state's failure to enforce child support payments, a stakeholder said, "*Many of our men are not deadbeat; we say they [are] dead broke*." She said fathers need to be better educated about the system and involved in their children's lives in multiple ways.

In determining how to address the identified needs, BFH considered extant programmatic approaches. Over the past several years, BFH has substantially invested in the quality of and access to reproductive health services, including integration in primary care and enrollment in family planning coverage. BFH is using data-driven strategies, like geocoding, to identify areas of the state where women are at increased risk for health problems for targeted intervention, determine provider coverage, and track utilization and access.

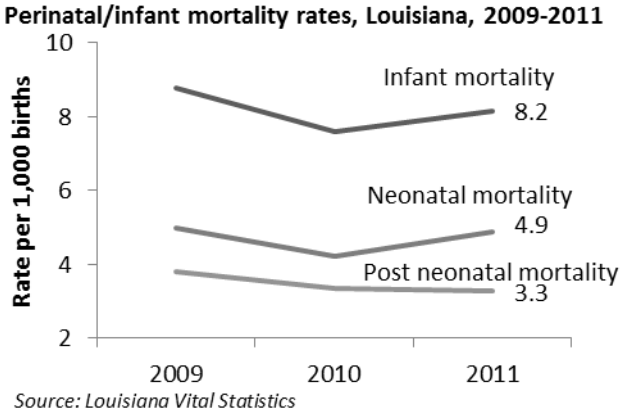
As BFH moves forward in the next five years, it will also consider solutions proposed by stakeholders and community members that are within BFH capacity. Stakeholders said that women should have better coverage for birth control and other health services, including follow-up care. One ob/gyn who sees many Latina patients in the New Orleans area identified a need for better translation services at clinics and hospitals.

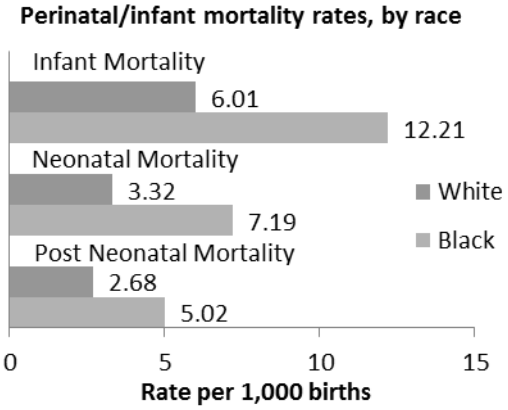
> *"Get contraception for all those who want it, the type they want."*
> –Ob/Gyn (BFH Stakeholder)

Across focus groups, women noted the need for better support networks. Women in opioid treatment, for example, have few social ties, as they have given up old friends who still use substances. They want to have "normal" friendships with others who will not judge them and who will understand their struggle. Other women mentioned the need for support groups for women who are pregnant, especially single mothers who lack family or social supports.

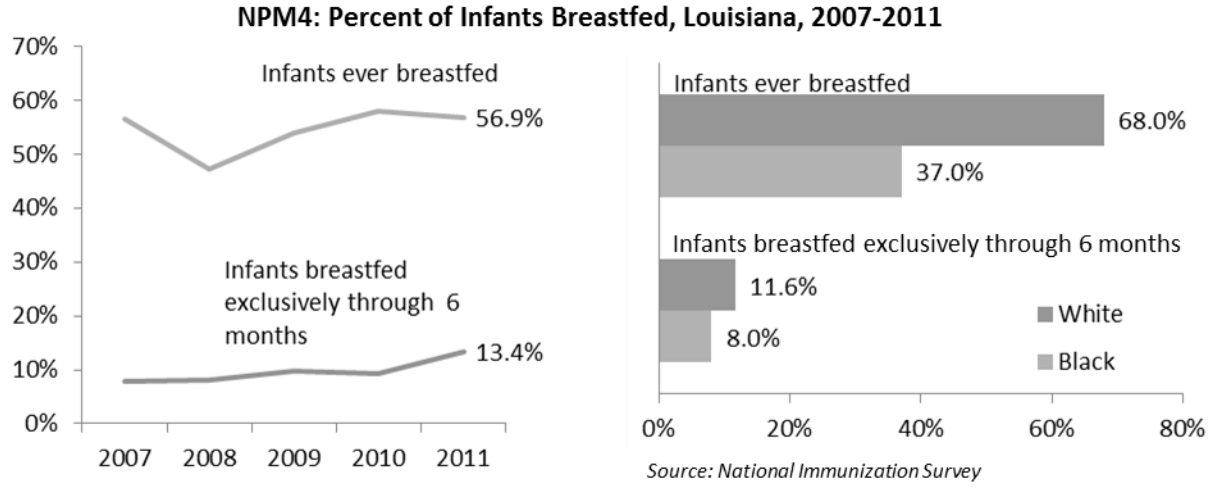
Perinatal/Infant Health

While BFH has made progress on some measures in recent years, like breastfeeding rates, Louisiana continues to rank low nationally on a number of indicators, and racial disparities on infant outcomes remain high.





In addition to addressing these issues by focusing on improving preventive and preconception care for women through well visits, BFH will **bolster local level capacity to promote and protect health and well-being of children, caregivers and families** as a Priority Need linked to **NPM 4: Breastfeeding** (% of infants who are ever breastfed and % of infants who are breastfed exclusively through 6 months) and **NPM 5: Back to Sleep** (% of infants placed to sleep on their backs)**.**



BFH has made long-standing investments in increasing awareness about the benefits of breast milk and in a hospital designation program, The Gift, for birthing centers that adopt evidence-based practices that promote breastfeeding initiation.

PRAMS data show that breastfeeding initiation is significantly higher in GIFT-designated facilities than in non-GIFT facilities.

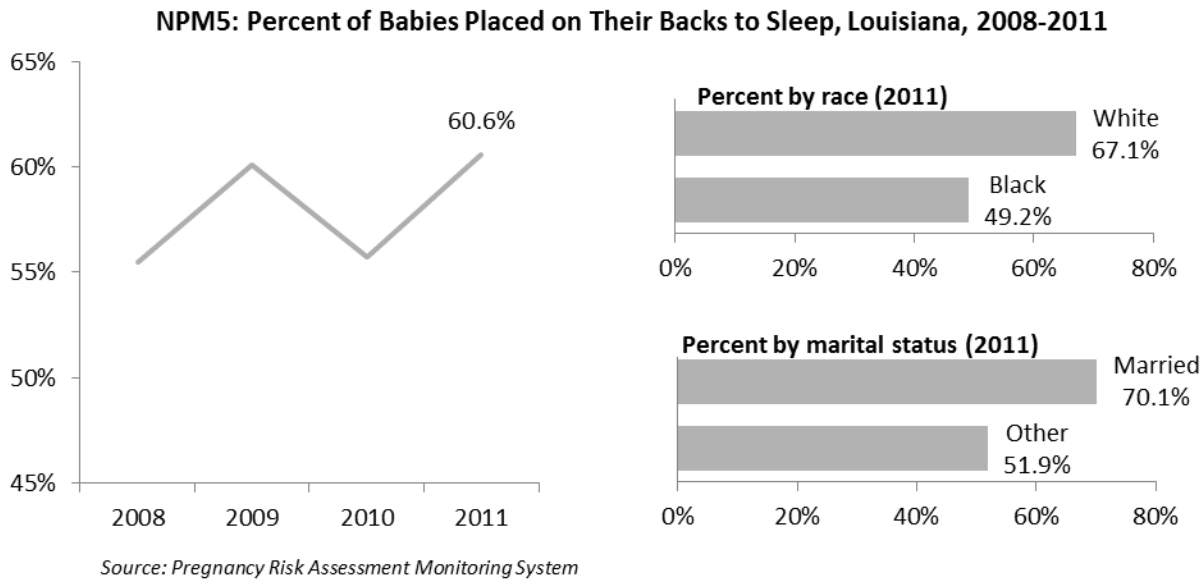
Louisiana is beginning to see progress, although data affirm work remains to be done. While some focus group participants said they breastfed their children, most did not – at least not for very long. One mother said she did not breastfeed because she was "a little embarrassed" to ask about it and did not receive any information about it from her doctor. Some mothers said they tried nursing in the hospital but stopped because it hurt or did not seem "sufficient." A few mothers said they breastfed for longer period of times in recognition that it was cost-effective, healthy, and promoted mother-child bonding. Data suggest that sustaining an investment in building knowledge about breastfeeding initiation and continuation is worthwhile. BFH plans to capitalize on momentum in this direction by continuing current strategies, like the alignment of community and hospital resources with the pro-breastfeeding message promoted in BFH materials and programs.

Nearly all of the women who participated in focus groups recited the guidelines about how babies should sleep – on their backs, alone, in their cribs. They are also aware of Sudden Unexpected Infant Death Syndrome (SUID) and its association with not following these recommendations. And while some women followed these guidelines, others did not. One mother said, "*I kind of ignored that [instruction on safe sleep for infants]. . . . They slept on their stomach, and I slept with them*." Some women said mothers' sleep was better and access to necessary items, like diapers, is easier if infants sleep with them.

36.2% of Louisiana women say they never co-sleep

-PRAMS, 2011

BFH will continue to focus on strategies that promote safe sleep such as changing social norms, increasing community support, and catalyzing policy reform. Current initiatives to prevent infant mortality due to sleep-related deaths in Louisiana include: the CDC-funded SUID Case Registry surveillance program, a social marketing and outreach campaign (Give your Baby Space), the Direct On Scene Education (DOSE) intervention for emergency first responders to educate about safe sleep as a part of any incident call, and the Safe Sleep Hospital Designation that recognizes hospitals adopting AAP guidelines. In addition, BFH is working with WIC, DCFS, and home visiting to ensure consistent messaging. Given the preventable nature of these deaths, greatly reducing them would have significant impact on both post-neonatal and overall infant mortality.



Source: Pregnancy Risk Assessment Monitoring System

One issue that has gained attention recently in Louisiana is Neonatal Abstinence Syndrome (NAS), or the exposure of infants to prescription and/or illegal drugs either in utero or shortly after birth. Data show that this trend is increasing in the state, as it is nationwide. Women who participated in the opioid treatment focus group described their anguish at watching their newborns go through withdrawal either from their illicit drug use or from prescribed methadone use.

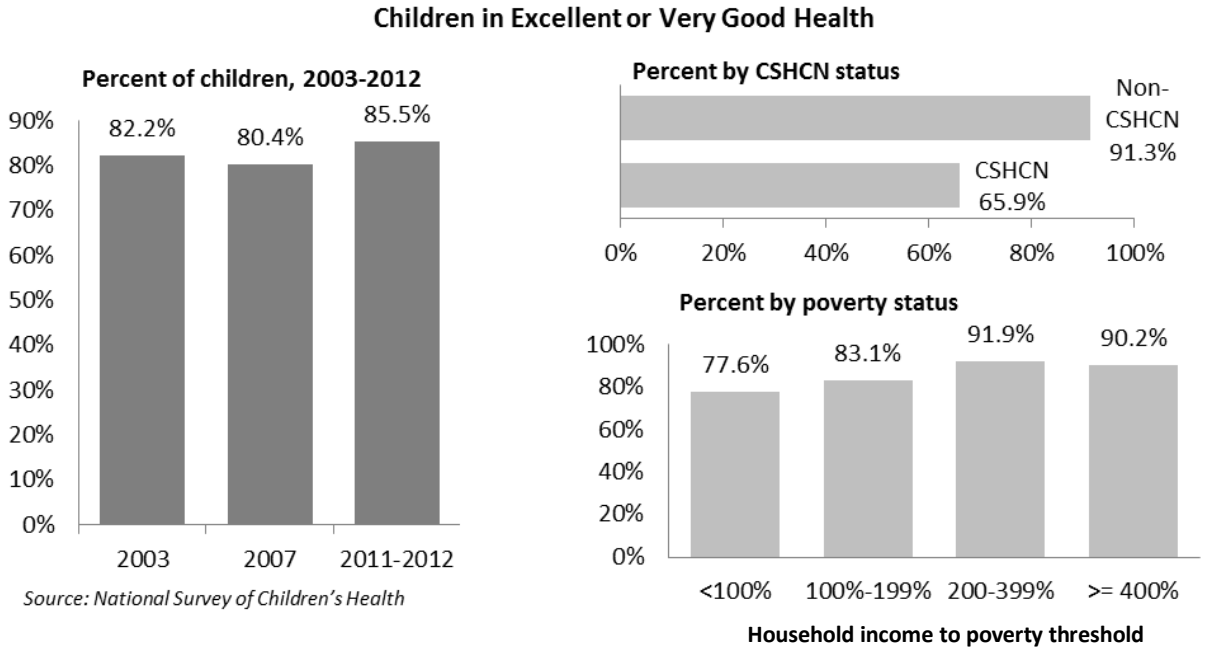
> *I didn't even get to see him for 8 hours, 'cause he was withdrawing so badly when he came out. He stayed in the hospital for 3 ½ weeks.*
>
> – BFH Focus Group Participant

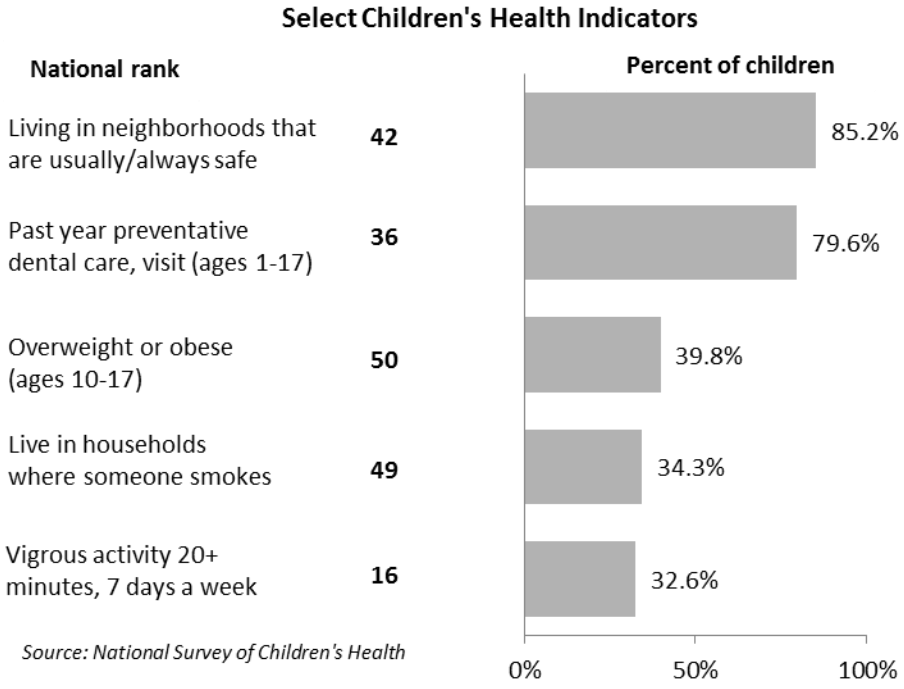
Medicaid is considering the inclusion of methadone in its formulary and is an engaged partner for BFH in the effort to curb NAS. BFH and Medicaid are currently working together on a Centers for Medicaid and Medicare Services (CMS) high-intensity technical assistance project around Substance Use Disorders, of which NAS has become a focal point.

In addition to continuing programs mentioned above and others that aim to protect the health of Louisiana infants, BFH appreciates various solutions proposed by focus group participants and stakeholders. On the issue of safe sleep, focus group participants suggested more parenting classes and extended home visitation programs. To improve breastfeeding rates, some women suggested providing classes for women after childbirth, good breast pumps, and better support for working mothers. Women in substance abuse treatment and those who work with them suggested more treatment centers for pregnant women, improved counseling options, support groups, and better education for opioid clinic directors and ob/gyns on pregnancy and substance use disorders.

Child Health

On a number of child health indicators, Louisiana fares well nationally, while on others, it ranks at or near the bottom.



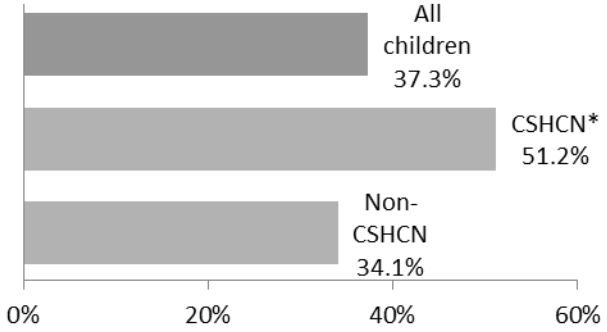


For this domain, in addition to the indicators noted in the Life Course section, BFH and CYSHCN Programs will prioritize **ensuring high performing essential MCH**

screening and surveillance systems. To measure this Priority Need, they will track **NPM 6: Developmental Screening**. They will also propose an SPM that monitors and improves timely detection and follow-up for children who screen positive for other conditions.

Early identification of developmental disorders is vital to healthy children and families, as is proper follow-up care and treatment.

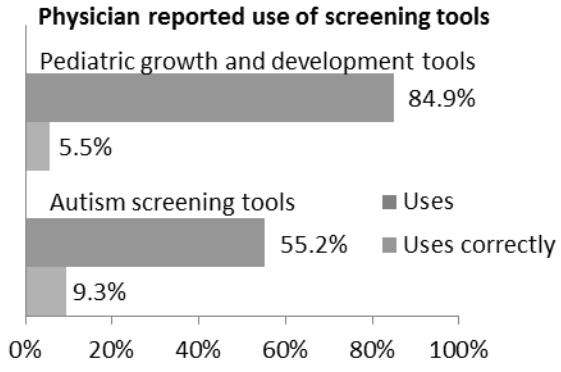
NPM 6: Percent of children receiving a screening using a parent completed screening tool, Louisiana, 2011-2012



Source: National Survey of Children's Health

While CYSHCN Physician Survey data suggest that family practitioners and pediatricians are using developmental and autism screening tools, the majority do not appear to be using them correctly. When physicians were given a list of the recommended developmental screening tools, 85% reported using at least one tool. However, when asked when they used the developmental screening tools, only 6% of physicians reported using them (Ages and Stages Questionnaire, Child Development Chart, Parents Evaluation of Developmental Status) at the correct times recommended by the AAP guidelines.

Physician reported use of screening tools



Source: Title V CYSHCN Physician Survey, 2015

Caregivers who participated in focus groups said there is a need for doctors to offer developmental screenings for children; several parents said doctors had disregarded concerns they raised about their children, who were later diagnosed with autism or

developmental delays. Some caregivers of autistic children expressed frustration that their concerns had not been heard by their children's providers, and then that the waiting periods for both evaluation and treatment were far too long when research points to the importance of early intervention.

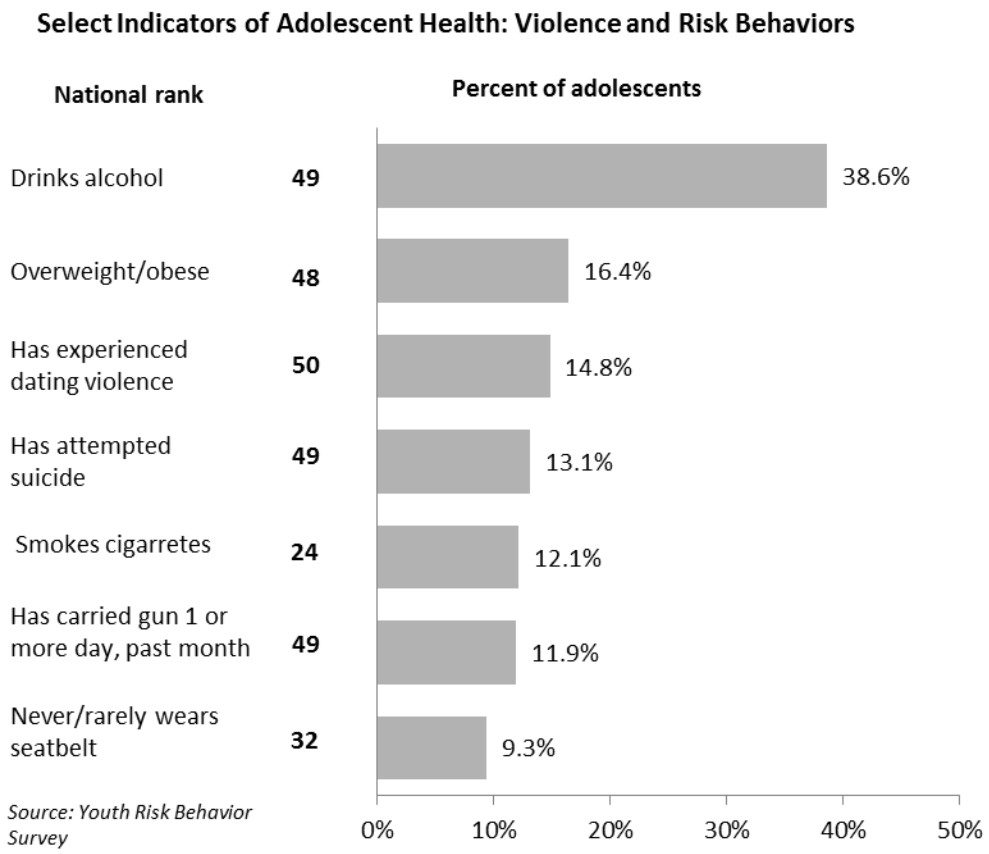
> *I thought I was a good advocate for him, but they kept saying it was first-time mommy, first-time mommy. And this is the pediatrician constantly telling me there was nothing wrong with him.*
>
> - CSHS Focus Group Participant
>
> *It took five months for them to finally . . . get everything started with him.*
>
> – CSHS Focus Group Participant

Though some BFH programs address developmental screening and CYSHCN Programs are interested in using the expertise of their staff to tackle this issue, no systemic monitoring of and response to developmental screening of children exists in Louisiana. The recent transition of Medicaid from fee-for-service to managed care Bayou Health plans, as well as changes within the safety net healthcare system, also point to the need to ensure Louisiana has a robust developmental screening system.

BFH is concerned about additional issues raised by focus group participants and stakeholders about the lack of safe places to play for children and community violence. Many focus groups participants said their younger children do not have safe places to play. Parents in several regions said they do not allow their children to go outside and play because they are worried about violence. Within the Life Course domain, Louisiana has identified cross-cutting Priority Needs that speak to some of these concerns, including efforts to strengthen community-level activities and systems to address child and family well-being and resiliency. The comprehensiveness of the Priority Needs – like focusing on community-level infrastructure change to address concentrated disadvantage – will also enable BFH to partner with consumers, stakeholders, and state partners to address social determinants which contribute to the inequities associated with obesity, lack of physical activity, community safety, and injury.

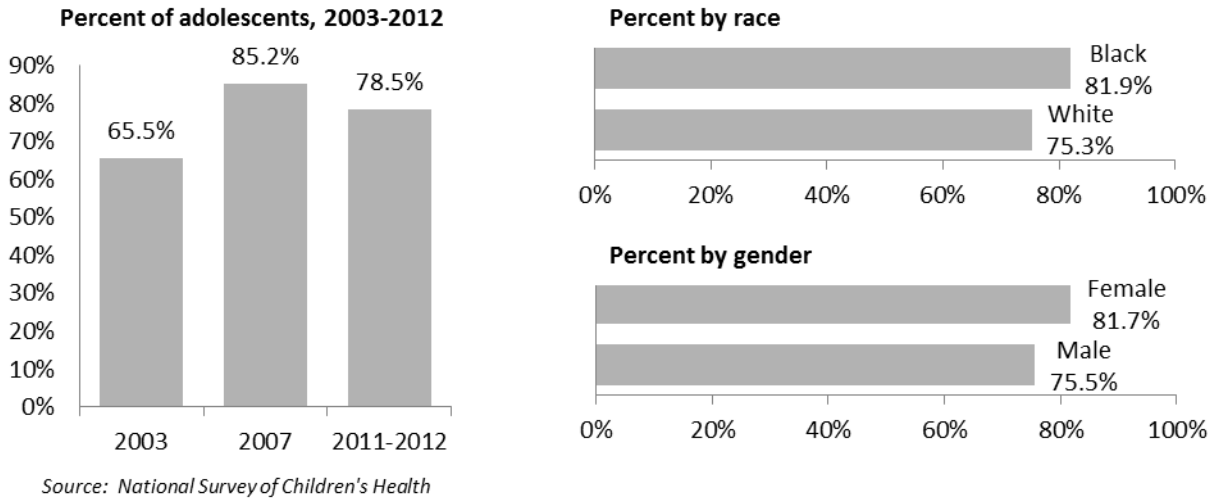
Adolescent Health

In recent years, Louisiana has shown improvement on some indicators for adolescent health status – including its teen pregnancy rate, seat belt usage, and smoking – but its standing at or near the bottom of state rankings on other measures tells a story of problems that need targeted attention.



One direct way to address these varied problems is by ensuring that all adolescents receive a preventive medical visit. Thus, a central focus for this domain will be to: **Improve access to and quality of primary care, reproductive health, and specialty clinical services including care coordination** as measured by **NPM 10: Adolescent Preventive Medical Visit**.

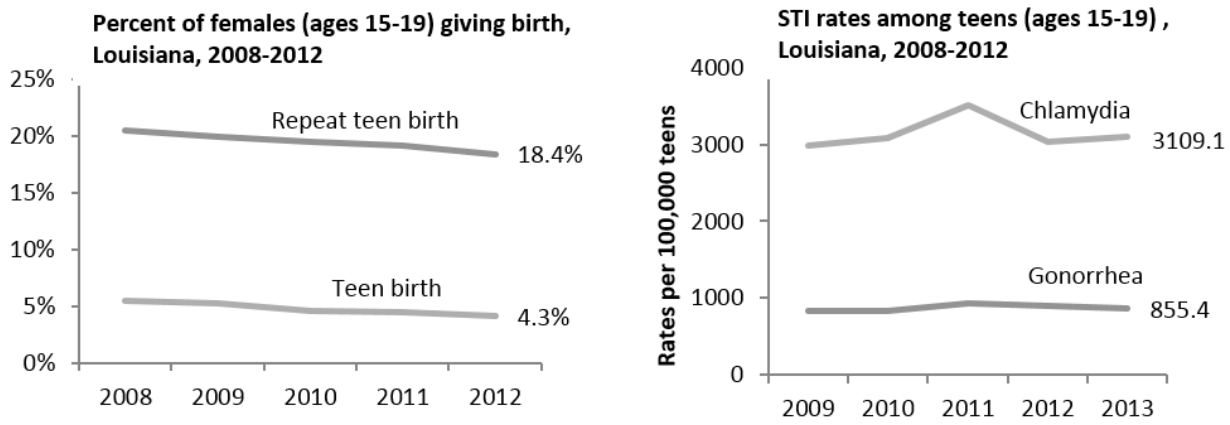
NPM 10: Percent of adolescents, ages 12-17, with preventive medical visit in the past year



Source: National Survey of Children's Health

Though this is not an NPM on which Louisiana ranks far worse than other states, its Title V efforts will continue to build on its programmatic investment in this area to capitalize on relationships with other programs. Recently, BFH initiated an adolescent health strategic plan work group that encompasses staff from CSHS, the OPH Adolescent School Health Program, the OPH Health Promotion (chronic disease prevention) Program, the OPH STD/HIV Program, and the DHH-Office of Behavioral Health Coordinated System of Care (CSoC) Program for children at risk for institutionalization or incarceration, as well as BFH reproductive health, teen pregnancy prevention, and home visiting programs. In addition, DCFS has indicated that there are opportunities to improve the linkage to healthcare for adolescents in and aging out of child protective services. BFH and CYSHCN Programs will seek to strengthen existing investments in reproductive health and adolescent transition approaches (see discussion of NPM 12 below) and to improve the health of Louisiana citizens as they move into adulthood.

Nearly all focus group participants – including the adolescent group – identified teen pregnancy and STIs as problems in their communities. When asked why teens were having sex, contracting STIs, and getting pregnant, one adult focus group participant said, "*Abstinence does not work. It is a fantasy, and we should just let it go*."



Source: **Louisiana Vital Statistics**

Prompted to explain why "*everybody's having babies,*" as one adolescent participant said, the teenagers with whom we spoke blamed their peers – often the girls themselves. One said, "*They think it's cute, or – having sex or trying to keep a dude, and they get pregnant, and it's like, 'Yeah, well*.'" Adolescent focus group participants said a lack of communication with and trust in adults are barriers to their feeling supported in general, but especially when they confront teen pregnancy or other consequences of risky sexual behavior.

> *And [teenage girls] feel like when you have sex with a boy, then that's trust . . . Then you have a baby and you feel like . . . that baby gonna be there for you and that baby gonna give you the attention that you need, but really, in reality, it don't work like that.*
>
> -BFH Adolescent Focus Group Participant

When asked how teen pregnancy might be addressed, adults emphasized solutions ranging from changing gender socialization practices to classes for adolescents that require them to take care of an object for a period of time. Nearly all participants said teen mothers should be supported and encouraged to remain in school.

As with other domains, BFH will monitor issues identified by community members and stakeholders as pressing for the health of Louisiana adolescents. When parents in one group were asked about the biggest problem facing their children, one person answered, "the streets," and the other participants murmured their assent. Like parents and caregivers in other groups, they identified a void for their children who were too old for after-school programs aimed at youth. This theme recurred across all focus groups – that teenagers have nowhere to go after school or during the summer and thus are susceptible to getting into various kinds of trouble or being endangered.

As long as they in school, you know where your kids at. You know they kinda safe. You praying to God that they be safe, but when that bell rang and they all – this city has nothing to offer them.

– Focus Group Participant

When the adolescent focus group was asked what they worry about, one male adolescent participant said, "*Too many young people got guns.*" For these youth – and for parents in at least one other focus group that addressed adolescent health – bullying is not an issue of concern. Some said schools' zero-tolerance policies on bullying have curbed its incidence. BFH acknowledges that this issue, while important, is largely the province of schools in Louisiana.

BFH stakeholders and BFH and CYSHCN focus group participants said schools need to do more to support Louisiana's youth. Caregivers in BFH and CYSHCN groups said school staff are not adequately trained to support CYSHCN. Parents of CYSHCN frequently described how they felt their children were pushed out of schools, because schools were unwilling to meet their children's needs. Concern was expressed by stakeholders that schools also push out children who do not meet inconsistently defined and enforced behavioral standards.

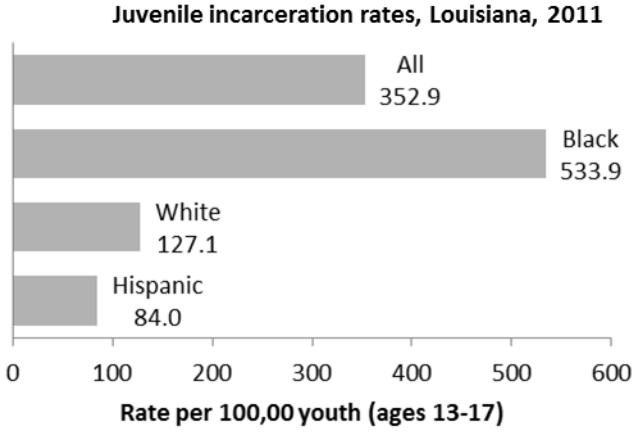
We have had horrible, horrible school experiences. The schools did not want him.

– CYSHCN Focus Group Participant

They don't know how to deal with her [child with autism] . . . like they call once a week. . . . And I go get her. She's not sick. They just don't want to deal with her.

- CYSHCN Focus Group Participant

Other stakeholders addressed their concerns about youth who are involved, or at risk for becoming involved, in the criminal justice system.



Source: National Center for Juvenile Justice/Bureau of Justice

Stakeholders described the toll a child's incarceration takes on families, noting that children are often placed in facilities located far away from their families who often do not have reliable transportation. One stakeholder explained that many youth in the juvenile justice system are "crushingly poor" and do not have a place to call home. He said support systems – like schools and mental health care systems – have failed them, and they need early intervention before these problems develop.

> *73% of children in Louisiana's juvenile justice system have a diagnosed mental illness.*
> – BFH Stakeholder

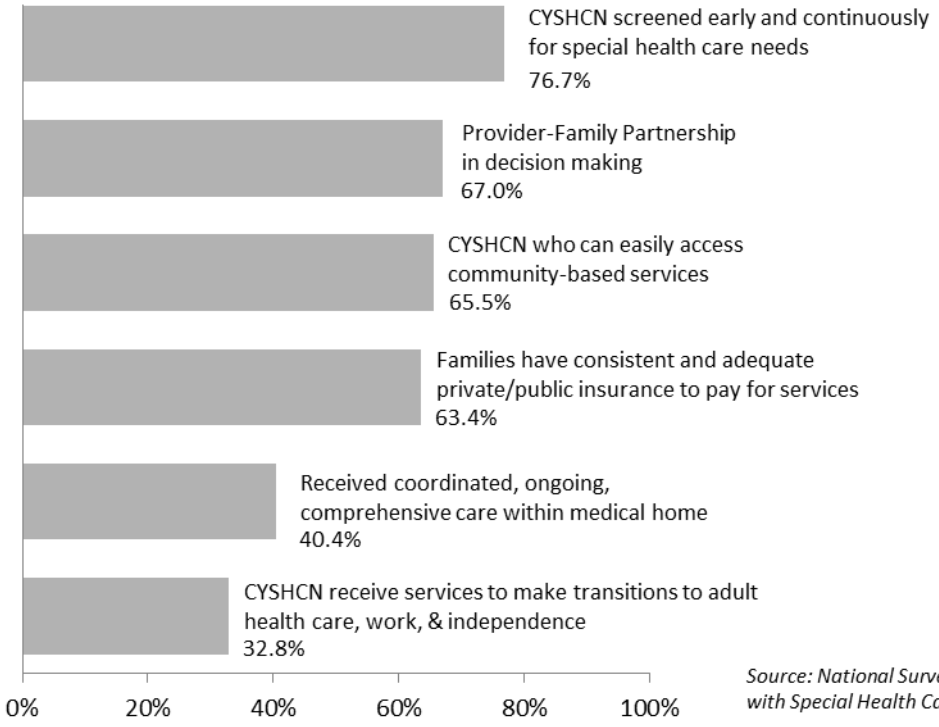
Finally, stakeholders identified a pressing need to address the mental health of Louisiana's adolescents, especially those in the juvenile justice system or at risk for being placed there.

Within the Life Course section, Louisiana has identified cross-cutting Priority Needs that speak to some of the concerns that are affecting adolescents' health and well-being. In particular, Title V plans will encompass efforts to strengthen community-level activities, improve family and child well-being and resiliency, and build local-level leaders, including youth.

CYSHCN

Data from the 2009/10 National Survey of Children with Special Health Care Needs (NSCSHCN) provide the most recent detailed information pertaining to Louisiana's CYSHCN.

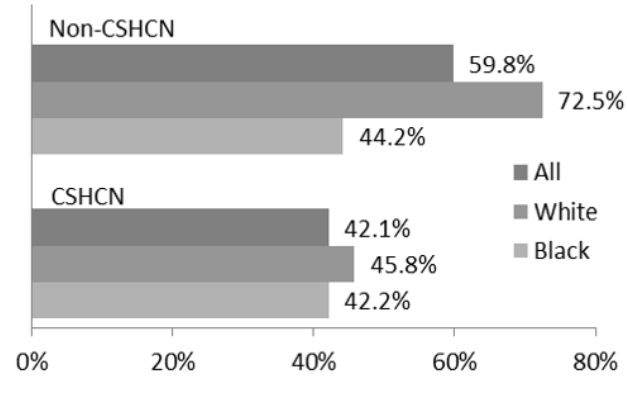
Select Indicators of CYSCHN Health Care Needs, Louisiana, 2009-2010



Source: National Survey of Children with Special Health Care Needs

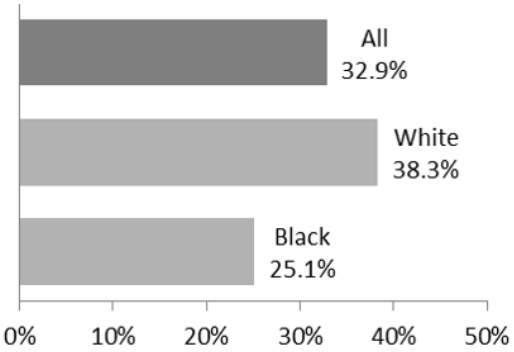
In consideration of these data, along with newly gathered qualitative data, the CYSHCN programs identified the following two Priority Needs for this domain: **1) Improve access to and quality of primary care, reproductive health, and specialty clinical services including care coordination,** measured by **NPM 11: Medical Home** and **2) Improve the ability of care systems to serve and support children, adolescents and CYSHCN through transitions** measured by **NPM 12: Transition Services**.

NPM 11: Percent of children with and without special health care needs having a medical home, Louisiana, 2011-2012



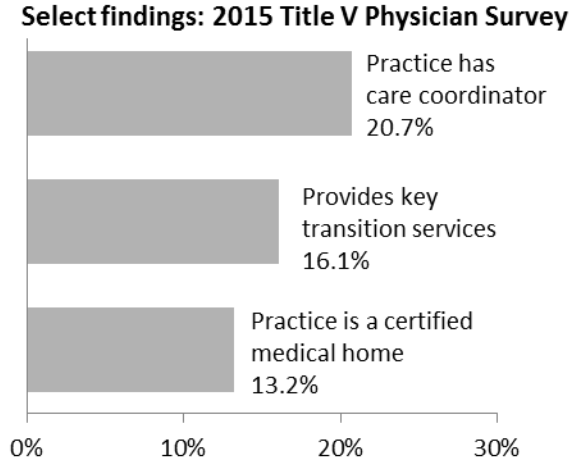
Source: National Survey of Children's Health

NPM 12: Percent of YSHCN who received services to transition to adulthood, Louisiana, 2009-2010



Source: National Survey of Children with Special Health Care Needs

Data collected for the needs assessment confirm medical home/care coordination (CC) for CYSHCN is an area in need of improvement. Pediatricians who responded to the survey are more likely to report having engaged in CC practices than are family practitioners. Most CYSHCN focus group participants could not identify a medical home, or center of CC, for their children. These caregivers said they provide CC for their children; however, many participants identified CSHS staff and Families Helping Families as important sources of assistance. Very few participants felt their pediatricians provide a medical home for their children. One parent said, "*There's no manual, and you've got to figure it out on your own*." Another said finding providers and figuring how to care for her child was "*like a scavenger hunt*." Some parents said that the current and former CSHS clinics provided at least some degree of CC. Speaking of the loss of the services provided by the now-closed New Orleans CSHS clinics one parent said, "*Everything was rolled into one. It was more convenient . . . Somebody kept up with me*."

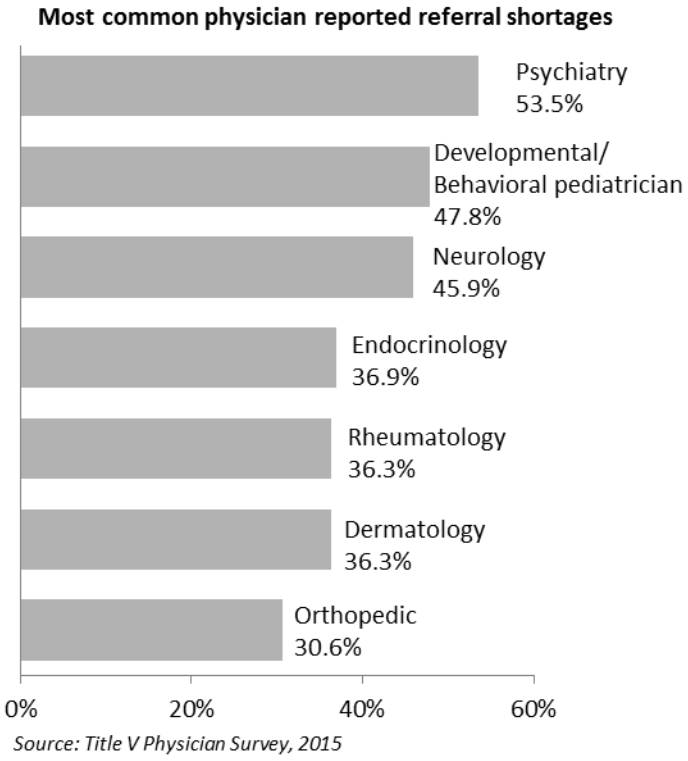


Data also indicate a need to improve transitions in care for CYSHCN. The 2009/2010 NSCSHCN found that only 32.8% of Louisiana's CYSHCN report having necessary services to make appropriate transitions to adult health care, work, and independence. This need is more pronounced among non-Hispanic Blacks, those who live below or near the poverty line, and those who have public insurance only. Only 16% of physicians who responded to the survey report that they provide all six key transition services. In focus groups, caregivers with children who have aged out of care or will soon transition to adult healthcare said they worry about whether their children will have health insurance coverage and continued access to specialists. Some caregivers said that their adult children had already lost health insurance and/or access to specialists. Even caregivers of young children said the transition out of Early Steps, at age three, left them feeling like they were on their own to navigate the system of care and to find and pay for services for their children, especially therapies. Summing up how many parents felt about their children leaving this program, one mother told us, "*After Early Steps, that's a wrap. You're on your own."*

When we had Early Steps we had speech, we had OT, we had a nurse, we had all these services that were provided to us and it didn't matter how much money you made. When you age out of Early Steps, you get nothing.

- CYSHCN Focus Group Participant

Physician survey data and focus group findings also suggest additional areas where health care services for CYSHCN could be improved. Physicians and focus group participants alike reported that CYSHCN need better access to subspecialists, especially in the areas of neurology, cardiology, and developmental behavior. Caregivers said that they often do not have access to the specialists their children need in their local area, and a number of families take their children out of state to receive specialized care. Both physicians and caregivers identified a need for assistance with understanding public health resources; many caregivers said they need more guidance navigating the system of care and choosing physicians.



Source: Title V Physician Survey, 2015

There's no pediatric ortho doctors anywhere around here close to me for when my son breaks and fractures. I care for him myself. I splint him myself. I take him to the ER if it's a major displaced fracture.

–CYSHCN Focus Group Participant

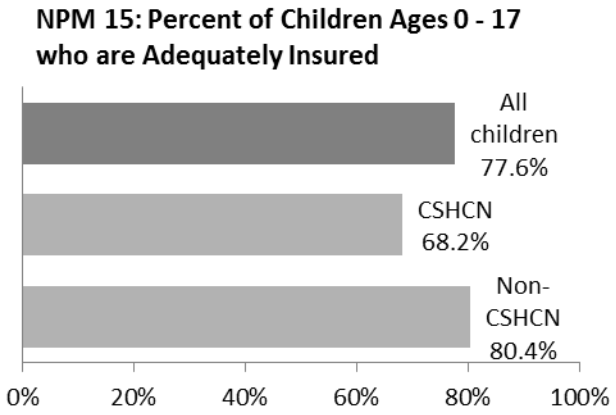
Caregivers who participated in CYSHCN focus groups raised a few additional areas of concern. In both urban and rural areas, they said that transportation is a formidable barrier to accessing care for their children; some struggle with public transportation in urban areas, while those in rural areas often have to travel long distances to see specialists. Caregivers also said their children's therapeutic needs are not being met, which they attribute in part to a shortage of therapists who accept Medicaid. For those families whose children do not yet receive the Louisiana New Opportunities Waiver or Children's Choice Waiver – and given the long waitlist, this describes most families represented in the focus groups – respite care is a pressing need.

CSHS has always provided CC in its specialty clinics, but since 2010, most of these have been closed due to budget cuts and health care reform. In recent years CSHS has focused on improving CC in medical homes by teaching CC in academic primary care clinics. Benefits of this approach have not yet been fully realized, as residents who have trained in the system have not had time to complete their training and begin their own practices. CSHS has also developed a series of eight webinars in collaboration with Louisiana's UCEDD for providers on caring for CYSHCN; topics include CC, transition, and developmental screening, but the webinars have not yet been posted due to technical difficulties and delays in gaining CME approval. "Lunch and Learns" have been approved for continuing education for nurses and social workers and will continue to be offered to private practices. CSHS has developed a CC toolkit for practices that has not yet been marketed to private practices. CSHS is exploring a CC implementation pilot with Louisiana Healthcare Connections (LHC), Louisiana's largest managed care organization (MCO), to study cost savings of CC in a medical home. This approach might lead to MCO financial support of CC. CSHS anticipates that CC in the medical home, including transition services, will improve with full implementation of these strategies. Future efforts will focus on family practitioners, since data indicate that they are less likely to use screening tools and less likely to refer to services most needed by families of CYSHCN. CSHS will also emphasize the inclusion of assistance with navigating insurance options as part of CC.

Cross-cutting/Life Course

Six of Louisiana's seven Priority Needs cross all three of the legislatively-defined population groups – pregnant women, mothers, and infants up to age 1; children; and CYSHCN – indicating the commitment of BFH and CYSHCN Programs to recognize, understand, and serve Louisiana families across the life course. The leadership of BFH and CYSHCN Programs created encompassing priority needs in recognition of the need for data- and community-driven attention to the drivers of public health disparities, as well as to the intergenerational nature of health and health disparities.

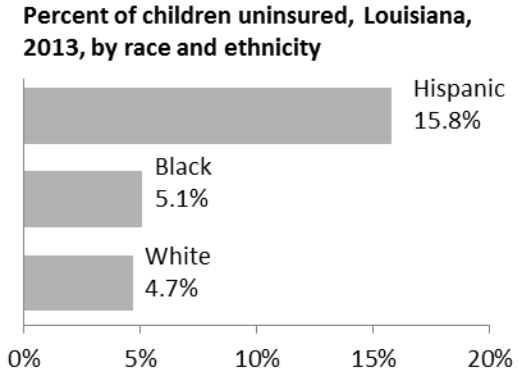
Of the three designated measures in the Life Course domain, Louisiana will focus on **NPM 15: Adequate Insurance Coverage, 0-17 years**. Though Louisiana performs well on measures of health insurance coverage for most age groups, BFH and CYSHCN Programs want to remain vigilant in monitoring and protecting consistent and adequate insurance coverage. While 97% of CYSHCN have health insurance, it is notable that only 68.2% of parents perceive it to be adequate.



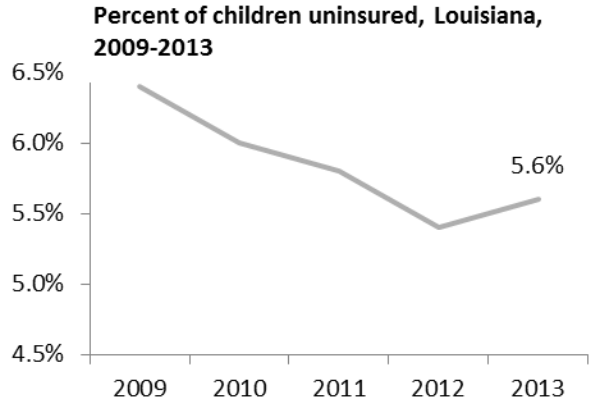
Sources: National Survey of Children's Health 2011-2012

In the last few years, Louisiana residents have seen many changes in the state's Medicaid enrollment processes, eligibility criteria, and benefits offered through the different managed care plans; they have also experienced changes in coverage with the transition to the new Federal MarketPlace for individuals and families that qualify. BFH and CYSHCN recognize a need to measure, understand, and address factors related to adequacy of coverage. The state will monitor this NPM to account for its ability to **improve access to and quality of primary care, reproductive health, and specialty clinical services including care coordination**.

Despite significant declines in the rate of uninsured children from 2003-2011, Louisiana witnessed a modest increase in both the number and percent of uninsured children from 2011-2013. All but one of the nine public health regions experienced increases in the rate of uninsured children, and disparity of coverage based on race, age and income is statewide.



Sources: American Community Survey, 2013



Sources: American Community Survey, 2009-2013

Qualitative data show variation in perceptions of adequate coverage across the life course. Many of the caregivers who participated in the BFH and CYSHCN focus groups said they are satisfied with insurance coverage for their children. One mother said, "*My*

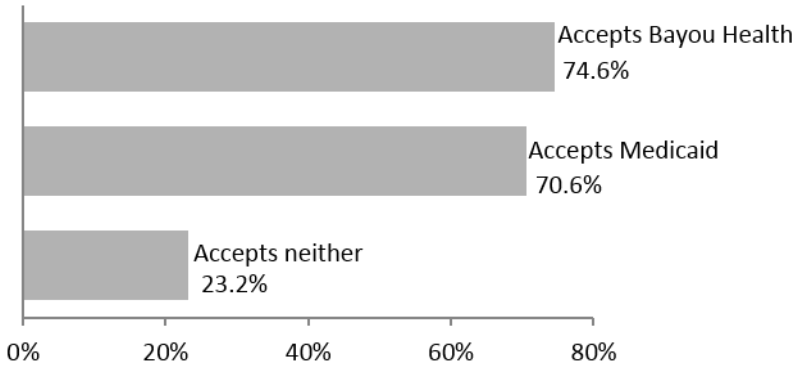
children have been getting Medicaid from day one. We've never had to pay for insurance for them." Others, however, said the current Medicaid plans do not provide full coverage that meets all of their children's needs, especially if the children have special health care needs. One parent of a child with special health care needs said that inadequate Medicaid benefits prevent her from providing the best care for her child: "*You have to fight for the little bit of income just to help your child with the resources they need . . . They'll deny you, deny you, deny you, deny you till you're blue in the face*." Nearly all caregivers who participated in the CYSHCN focus groups – both those who receive Medicaid and those who do not qualify for most or any state assistance – said that they struggle to afford adequate, quality healthcare, services, and supplies for their children.

> *It shouldn't be so hard for us to get diapers and wheelchairs and supplements and medication and therapies and other needs. Why is it so hard? Why is it?*
>
> – CYSHCN Focus Group Participant

Though some caregivers said Medicaid covers their children's needs, others said the financial costs are burdensome, and their struggles to get coverage are frustrating. Caregivers who participated in focus groups expressed frustration with the Bayou Health Plans, because they said these plans prevent them from accessing adequate care for their children, including specialists, therapies, and supplies. When they could, parents switched their children's coverage to traditional Medicaid. Still, many remain confused about whether or not they have this option for their child with special health needs.

Given Louisiana's privatization of Medicaid since the last needs assessment, CYSHCN Programs were especially interested in physician acceptance rates of the various Medicaid plans. Data show that most physicians accept Bayou Health or traditional Medicaid, although almost one-fourth who participated in the CYSHCN Physician Survey accepts neither. Pediatricians are more likely to accept either Bayou Health or traditional Medicaid plans than are family practitioners.

Percent of Physicians Accepting Public Insurance



Source: Title V CYSHCN Physician Survey, 2015

While many BFH focus group participants said their children have adequate coverage, they did not describe their own health coverage in the same way.

22% of Louisiana adults (ages 19-64) are uninsured
- 29% of Black adults are uninsured
- 18% of White adults are uninsured

-Louisiana Health Insurance Survey, 2013

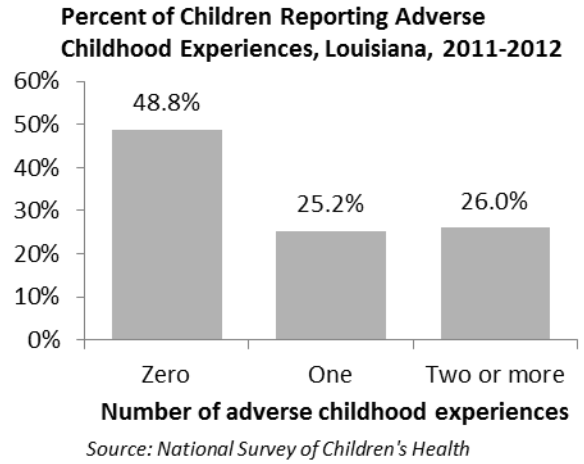
A stakeholder working in the area of health insurance enrollment encouraged state agencies like BFH to "*sit down with us and our coalition*" to provide information about health insurance coverage – and ways to afford it – to their clients. In an effort to improve the overall health system landscape in Louisiana, BFH and CYSHCN Programs have completed the *Title V State Access to Care Assessment Tool* and will be working with the MCHB Workforce Development Center to develop a comprehensive plan.

In addition to addressing heath care access through NPM 15, the other Priority Needs in this domain represent Louisiana's intention to preserve and strengthen capacity around core public health functions, advance cross-cutting strategies to improve systems, engage local communities in improving health services and protective factors, and build local level leaders across the state. Strategies and SPMs have been drafted and will be refined over the first year of the new grant cycle.

One of the essential public health services is to monitor health status to identify and solve community health problems. BFH and CYSHCN Programs are prioritizing the need to continue to build and **ensure high performing essential MCH screening and surveillance systems**. This Priority Need speaks to the intention to ensure robust analytic capacity for monitoring key indicators of MCH, well-being and risk. BFH has developed capacity to link data systems, map geocoded data, and analyze complex indicators such as Concentrated Disadvantage. In addition, staff are working to increase

analytic capacity using hospital discharge, medical claims, and emergency department data.

Throughout the Needs Assessment processes, families and stakeholders identified violence, trauma, substance use, and behavioral health as significant concerns in their families and communities. As a means to address this issue, the state has chosen the following Priority Need: **Improve social and behavioral health supports, with a focus on child and family well-being and resiliency.** One stakeholder who works in the area of juvenile justice said of many of his clients: "*exposure to trauma, both chronic and acute, is a regular aspect of [their] lives.*" NSCH data show that over half of Louisiana children have experienced at least one of the following Adverse Childhood Experiences (ACEs): (1) socioeconomic hardship, (2) divorce/separation of parent, (3) death of parent, (4) parent served time in jail, (5) witness to domestic violence, (6) victim of neighborhood violence, (7) lived with someone who was mentally ill or suicidal, (8) lived with someone with alcohol/drug problem, (9) treated or judged unfairly due to race/ethnicity.



BFH is interested in monitoring and addressing the effects of traumatic experiences and stressors on the lives of all MCH populations, especially children and pregnant women. BFH and CYSHCN Programs will be reviewing the scope and scale of investments related to social and behavioral support for MCH populations, including: Maternal, Infant, Early Childhood Home Visiting (MIECHV) services; mental health consultation supports to primary care and other MCH providers, such as those being piloted in Project LAUNCH; brief evidence-based grief interventions for children and families; efforts to build capacity around Adverse Childhood Experiences across systems; prevention of child maltreatment; and improvements in access to and quality of behavioral health services. Louisiana's SPM to address this Priority Need will be to develop a benchmark plan that will identify priority focused improvements for social and behavioral health supports for MCH and CYSHCN.

Many MCH outcomes are ultimately impacted by the "health" and systems of local communities. As such, Louisiana has identified a Priority Need to: **Bolster local level**

capacity to promote and protect health and well-being of children, caregivers and families. Both BFH and CYSHCN Programs have staff who are based in the regions and communities throughout the state, including: a statewide system of Regional MCH Coordinators who monitor MCH outcomes and work with local partners for action; statewide Birth Defects surveillance staff; and CYSHCN Parent Liaisons who serve as local resource hubs. In addition, BFH and CYSHCN Programs staff support quality improvement initiatives with hospital systems and local care providers. Lastly, epidemiology and programmatic staff serve as "subject matter experts" and resources to support local level entities in shaping grants and service priorities. An untapped area is how to bring epidemiology data "alive" and into the hands of businesses and local economic development entities who are employing and shaping their communities. To this end, BFH and CYSHCN Programs plan to develop an SPM to include a benchmark plan to provide community-specific information regarding health and economic outcomes to local leaders to spur and support community level action.

Many of the selected NPMs and Priority Needs are characterized by significant inequities, including race, geographic location, and CYSHCN status. Thus, another Priority Need is: **Advance understanding of drivers of disparities in MCH and CYSHCN outcomes and boldly work toward equity**. Data discussed in the sections above show consistent disparities across populations; the two programs will continue to work toward developing an even better understanding of what drives disparities and how the state can most effectively address them. For example, BFH has begun mapping areas of concentrated disadvantage to understand the social determinants of health and identify areas that intersect with significant disparities in MCH outcomes.

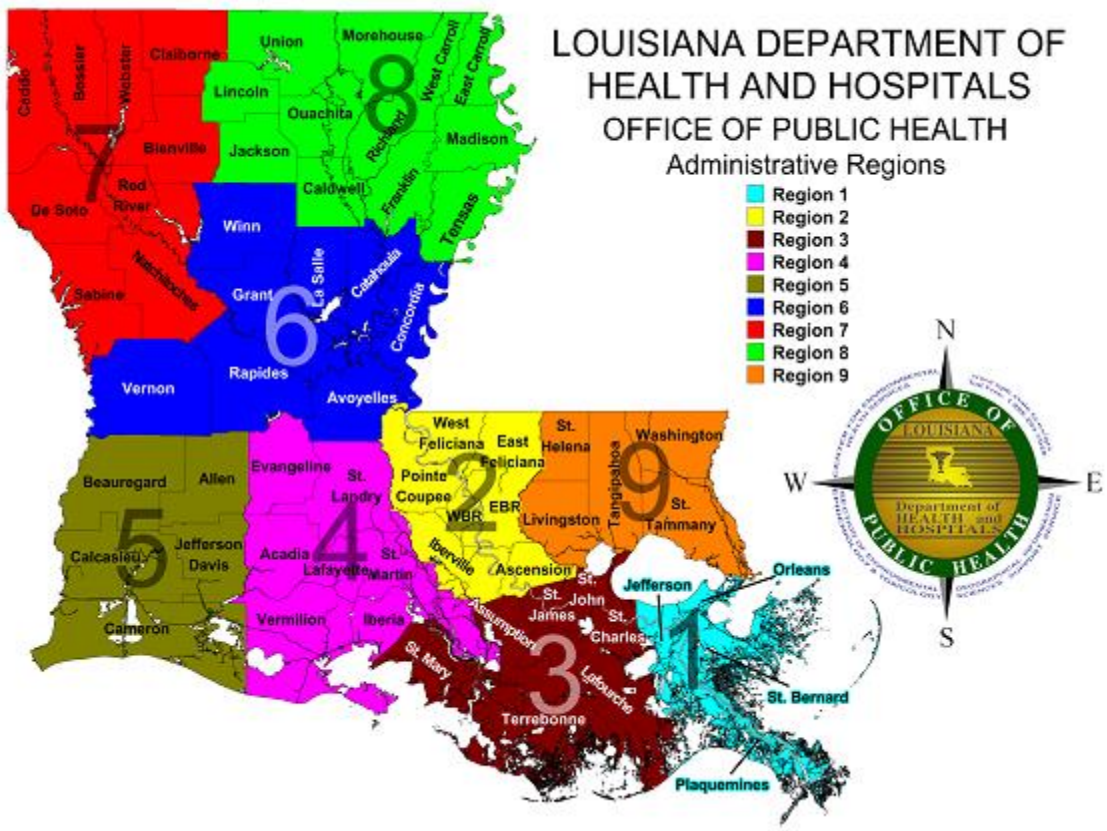
Lastly, BFH and CYSHCN Programs are committed to strengthening the participation of families and communities in the development and sustainment of Title V activities. Both BFH and CYSHCN Programs collected data via focus groups to hear the voices of the populations served by their programs. During data collection, participants stated how appreciative they were that their voices were invited and heard. As such, Louisiana has identified a Priority Need to: **Actively and meaningfully engage youth and families, building local level leaders across the state.** Working through community partners, BFH and CYSHCN Programs will identify individuals interested in serving in an advisory and advocacy role. BFH is developing regional Community Cafés that will engage communities around how well our services are meeting their needs. In addition, BFH and CYSHCN Programs will seek to formalize youth and family leadership development opportunities. Working together, Louisiana's Title V programs aim to continue to incorporate the voices of Louisiana citizens, especially by drawing on the rich history of CYSHCN Programs engaging families of CYSHCN in the development of local leaders.

III. Organizational Structure

Louisiana's Title V grant is administered through BFH and CYSHCN Programs, which are housed within the Louisiana Department of Health and Hospitals (DHH), Office of Public Health (OPH), Center for Community and Preventive Health (CCPH). DHH is one of 20 departments that report to the Governor, and its charge is to protect and promote

health and to ensure access to medical, preventive, and rehabilitative services for all citizens of the state (see Appendix C for Organizational Charts).

Louisiana has a largely centralized statewide public health system. OPH leadership and programmatic offices are located in Baton Rouge and New Orleans; Regional Administrator/Medical Directors oversee local public health responses and public health services through the 64 OPH Parish Health Units in each of the state's nine DHH administrative regions.



OPH provides personal health services including reproductive health services (family planning/STD), immunizations, and limited CYSHCN clinical services, all supported in part through Title V; other services not supported by Title V include WIC, tuberculosis control, and emergency response. BFH and CYSHCN Programs work closely with other OPH sections to plan and implement Title V efforts.

BFH includes five teams: Data to Action (DAT); Communications, Innovation, and Action (CIA); Clinical Services; Supportive Services; and Business Operations. CYSHCN Programs include four programs: Children's Special Health Services (CSHS), the Louisiana Birth Defects Monitoring Network (LBDMN), Hearing, Speech, and Vision (HSV), and Genetics. See the Workforce Development and Capacity section for descriptions of these Title V-funded programs.

IV. Agency Capacity

The Title V Block Grant supports the capacity of BFH and CYSHCN Programs to promote and protect health and well-being across the six MCH population health domains. It funds health services, health education and promotion, monitoring and evaluation, professional training, and policy development.

Women's/Maternal Health – BFH promotes and protects the health of women and mothers through comprehensive reproductive health services and provides limited behavioral health services related to trauma, depression, and loss. BFH's long-standing health education program, Partners for Healthy Babies, provides a website and toll-free helpline to pregnant women and families with young children, as well as access to resources through social media and texts. BFH engages in data-driven monitoring of the health of women and mothers by collecting and reviewing data on pregnancy experiences and maternal mortality. Finally, BFH participates in the coordination of policies and program development for women and mothers by serving on various councils (including the Louisiana Commission on Perinatal Care and Prevention of Infant Mortality and the state's Behavioral Health Planning Council).

Perinatal/Infant Health –The state's evidence-based home visiting programs support pregnant women and their families to the child's second birthday for the Nurse-Family Partnership model and to age 5 for the Parents as Teachers model. Title V provides some support for these services which have been expanded through the federal MIECHV funding. Through a multimedia statewide campaign, BFH provides education and professional training at the community level to reduce infant deaths due to SIDS and unsafe sleep environments. BFH monitors the state of infant health and well-being through routine analysis of Vital Records data and the Fetal Infant Mortality Review. BFH offers training to medical, child care, and other professionals who work with families with young children, with a particular focus on infant mental health, prevention of child deaths, and health and safety. Finally, BFH participates in or manages various programs that seek to advance child care options for young children, child and family well-being, breastfeeding-friendly policies, and healthy eating and nutrition.

Child Health –MIECHV services continue through early childhood. BFH also supports limited crisis intervention for children and families who have experienced violence and trauma. BFH and CYSHCN Programs monitor the state of child health through analysis of indicators of child health and well-being, including information from population health surveys, US Census Data, lead screening, child maltreatment data, and medical claims. State and local panels monitor and review the unexpected deaths of children <15 years of age. Finally, BFH is involved in initiatives to prevent childhood obesity and increase physical activity, improve health policies and practices in childcare settings, promote school readiness, and strengthen child well-being and resiliency.

Adolescent Health –BFH is working to strengthen the agency's approach to serving adolescents. The state largely focuses its efforts in the area of reproductive health services and evidence-based pregnancy prevention efforts to inform and educate

adolescents about responsible decision-making, family planning, and healthy behaviors. It also encourages parents to vaccinate children against Human Papillomavirus (HPV), Meningitis, Flu, and Hepatitis. Finally, BFH coordinates the CDC-funded sexual violence prevention initiative in the state which are overseen by the state Title V MCH Director.

CYSHCN – CYSHCN Programs provide family-centered, comprehensive, coordinated services for CYSHCN who meet medical and financial criteria through regional CSHS subspecialty clinics, although state budget cuts have reduced the number of clinics from 80 to 21 over the past five years. Staff at these clinics link patients with a medical home, and clinic social workers and parent liaisons link families to community resources and provide family support. YSHCN receive transition services to optimize vocational and healthcare independence. These clinics provide services for CYSHCN who receive SSI Title XVI benefits and meet state legislated medical eligibility criteria. CSHS supports some private clinics for CYSHCN, including two statewide cystic fibrosis clinics, a diabetes clinic, and a dental clinic. CYSHCN Programs also provide: newborn hearing and genetic screening and follow-up; technical assistance to embed medical home concepts into physician practices and resident training programs; active birth defects surveillance and monitoring; and transportation assistance.

For both BFH and CYSHCN Programs, achieving the mandate to ensure a statewide system of services is founded in three key approaches: 1) ensuring robust analytic capacity to identify needs and guide action; 2) actively cultivating collaborative partnerships with state and community agencies and professional organizations; and 3) maintaining a strong network of local level partners.

Data to guide action: Both BFH and CYSHCN Programs are anchored by data to inform services, policy and education initiatives, and system improvement efforts. Title V supported epidemiologists have been instrumental in determining priorities and populations served. CSHS staff have used data to guide action by employing web-based data systems to track screening and surveillance of newborn hearing loss and genetic abnormalities to ensure access to comprehensive follow-up care, birth defects monitoring to inform prevention campaigns and to identify and investigate local clusters for possible environmental causes, and lead screening to provide case management and environmental investigations to prevent lead poisoning. Web-based, integrated data systems provide the essential foundation for core public health functions.

State level partnerships: BFH and CYSHCN Programs actively engage with key state agencies including the DHH Medicaid Program, DHH Office of Behavioral Health (DHH OBH), DHH Office for Citizens with Developmental Disabilities (DHH OCDD), Department of Children and Family Services (DCFS), the Section of Environmental Epidemiology and Toxicology, and Department of Environmental Quality (DEQ).

Community-level partnerships: BFH and CYSHCN Programs have staff networks in each of the nine regions; networks include service providers and staff who work closely with the care and support systems in their local areas. In addition, the CYSHCN

Programs contract with clinicians for gap-filling services and entities that provide resources and support directly to CYSHCN families.

V. Workforce Development and Capacity

Between 2011-2012, MCH was reorganized into cross-cutting teams and integrated another anchor public health program affecting MCH outcomes – Family Planning – into BFH (See Appendix C for MCH Senior Level Management descriptions and organizational charts). The reorganization stemmed from three important beliefs: 1) program staff are content experts, 2) the new structure would better utilize staff expertise and advance shared goals, and 3) integration would help ensure BFH is both effective now and prepared for the future.

BFH Teams	Description	Total FTEs *
Data to Action (DAT)	• Monitor health and well-being through surveillance and data linkage • Provide timely, actionable data to support planning, policy development, & evaluation • Evaluate service accessibility and quality • Provide analytic support to the Title X Family Planning Program; the Maternal, Infant, Early Childhood Home Visiting Program (MIECHV); mortality surveillance, & the Pregnancy Risk Assessment Monitoring System	11
Communications, Innovation, and Action (CIA)	• Develop engaging public-facing products and information • Provide a link for public-to-state resources • Coordinate statewide health information campaigns and provider education • Cultivate a statewide network to identify & facilitate community and health system level issues and actions • Coordinate the Title V helpline and website • Work with hospitals and early care and education systems focusing on breastfeeding and obesity prevention • Support a statewide network of MCH Coordinators • Facilitate BFH orientations and professional development	19.93
Clinical Services	• Manage the Reproductive Health Program (RHP) through 64 OPH Parish Health Units & 2 contract sites • Develop a Reproductive Health Quality Collaborative to expand high quality family planning services in community-based settings • Administer adolescent pregnancy prevention services • Improve the visibility of RHP services and expand enrollment in available coverage options	100
Supportive Services	• Lead the state's MIECHV program and infant mental health services • Administer other early childhood system projects to address attachment, toxic stress, grief, and trauma	162.5
Business Operations	• Manage administrative functions, budgeting, contracting, grants management, and revenue cycle management • Responsible for the BFH budget of approximately $58.6 million, 18 funding sources, and 83 contracts	9.5
* FTEs are funded in total or in part by Title V and the state partnership.		

CYSHCN Programs consist of the four programs described below. In total, 16 parents of CYSHCN and one YSHCN serve as Title V program staff; eight parents and one YSHCN work in statewide activities, and eight work as regional parent liaisons. All are paid for their time and travel.

CYSHCN Programs	Description	Total FTEs
Children's Special Health Services (CSHS)	• Assures that CYSHCN have access to family-centered, community-based, coordinated, culturally competent, and seamless system of health care services • Provides enabling, population-based, and infrastructure building activities that enhance care and services • Provides direct services for eligible CYSHCN in CSHS clinics, including subspecialty care, care coordination, family support, and supplies • Serves as fiscal intermediary and payer of last resort • Provides transition services (medical, vocational, and independence needs) for YSHCN • Provides and trains academic primary care clinics and private pediatric offices to assist them in care coordination so they will become more effective medical homes • Provides transportation stipends through Families Helping Families for medical appointments	37.5
Louisiana Birth Defects Monitoring Network (LBDMN)	• Provides active surveillance of birth defects by collecting data on birth defects in children ages 0-3 from hospital discharge summaries and other data sources • Provides information to families of children with birth defects on locally available services • Performs analysis of collected data to determine frequency and distribution of birth defects in state • Uses data to plan and target birth defects prevention	8.5
Hearing, Speech, and Vision (HSV)	• Early Hearing Detection and Intervention (EHDI): provides universal newborn hearing screening, follow-up, and early intervention • Provides CSHS audiology clinics in areas with no audiologists that accept Medicaid for hearing aids • Purchases and dispenses low-cost hearing aids • Provides vision screens: preschool & school-age children	7.48
Genetic Diseases Program	• Newborn Screening: Screens all newborns with heel stick screen for 28 conditions; refers those who screen positive to Genetics Clinics • Childhood Lead Poisoning Prevention Program: Monitors blood lead levels in children 6 and under; identifies children with elevated levels; conducts environmental investigations for positive screens; works with families on remediation and care coordination; provides community and professional education • Sickle Cell Program: Provides in-state referrals to hematologists; provides SCD clinics in three regions; supports sickle cell foundation to assist families with care coordination	9

BFH partners with the People's Institute for Survival and Beyond to better understand drivers of persistent racial disparities in health outcomes. Staff and partner training includes workshops, video discussions and other learning activities. One outcome of these efforts was the completion of a BFH research project *Knowing Our History: Exploring Policies and Practices that Have Contributed to Racial Disparities in Health Outcomes.* This project included the development of a training resource, *Talking About Racism: A Toolkit for Honest, Respectful, and Productive Conversations* and earned BFH recognition at the national annual AMCHP meeting. In addition, BFH has actively sought to strengthen analytics and communications approaches around the *Concentrated Disadvantage* Life Course Metric through an AMCHP collaborative.

Title V CYSHCN Programs promote and provide culturally competent approaches in service delivery by analyzing Title V measures by race and ethnicity. In addition, central office and regional staff are racially and ethnically diverse, reflecting the population served. An HSV parent liaison fluent in Spanish, English, and American Sign Language translates program materials into Spanish for all CYSHCN programs including the block grant summary. Finally, regional clinics have access to phone interpreters for over 200 languages through a contract with Language Line.

VI. Partnerships, Collaboration, and Coordination

BFH and CYSHCN Programs have an extensive history of coordination, collaboration and partnership with organizations and programs that serve Louisiana's MCH populations.

Federal-Level Collaborations: BFH and CYSHCN Programs' partners at the national and federal level provide funding resources and technical assistance, as well as guidance on best practices and emerging trends in prevention and service provision.

State-Level Collaborations: BFH and CYSHCN Programs have been working to formalize collaborations with state level partners to ensure effective and successful partnerships.

Collaborations with Hospitals: Over the past several years BFH has worked diligently to strengthen its relationship with the 52 birthing hospitals statewide, successfully engaging many of them to promote breastfeeding and to actively support the American Academy of Pediatrics' *Recommendations for a Safe Infant Sleeping Environment* and *The Ten Steps to Successful Breastfeeding*.

Collaborations with Other Public Health Agencies and Universities: Ongoing collaborations with various local public health agencies and universities serve to expand the capacity of BFH and CYSHCN Programs.

Community Level Partnerships: Partnerships with community organizations and programs are vital in helping BFH and CYSHCN Programs carry out the Title V mission through planning, implementation, and evaluation.

Family/consumer Partnerships play a valuable role in BFH efforts and CYSHCN Programs. Given the state's priority needs, they will actively grow and cultivate these relationships in the coming years to affirm the commitment to addressing health and well-being across the life course.

BFH and CYSHCN Programs' Partners	
Level	**Partners**
Federal/National	• **Granting entities:** Health Resources and Services Administration (HRSA); Office of Population Affairs (OPA); Centers for Disease Control and Prevention (CDC); Substance Abuse and Mental Health Services Administration (SAMSHA); Graduate Student Epidemiology Program (GSEP); Kellogg Foundation; Robert Wood Johnson Foundation • **Other federal entities:** Environmental Protection Agency; Department of Housing and Urban Development; U.S. Consumer Product and Safety Commission • **Associations:** Association of Maternal and Child Health Programs (AMCHP); Nat'l Family Planning and Reproductive Health Association (NFPRHA); Nat'l Center for Birth Defects and Developmental Disabilities (NCBDDD – this is part of CDC) • **Advisory, advocacy, & resource groups:** Nat'l Birth Defects Prevention Network; Nat'l Healthy Mothers, Healthy Babies Coalition's Text4baby; Secretary's Advisory Committee on Heritable Disorders in Newborns and Children; Council of State and Territorial Epidemiologists (CSTE) • **Professional associations:** American Academy of Pediatrics (AAP); American Congress of Obstetricians and Gynecologists (ACOG)
State	• DHH Bureau of Health Services Financing (Medicaid Program and its five managed care plans) • DHH Office of Behavioral Health (OBH) • DHH Office of Citizens with Developmental Disabilities-Early Steps • DHH OPH Health Promotion, STD/HIV, Immunization, Nutrition Services/WIC, State Registrar and Vital Records, Center for Population Health Informatics, Section of Environmental Epidemiology and Toxicology (SEET) • Department of Education (DOE) • Department of Child and Family Services (DCFS) • LA Chapter for AAP; LA ACOG; LA Academy of Family Physicians • Louisiana Rehabilitation Services • LA School of the Deaf (Parent Pupil Education Program) • LA Association for the Deaf • Louisiana Primary Care Association (LPCA); Louisiana Rural Health Association (LRHA) • March of Dimes • LA Commission for the Deaf; Infant Hearing Advisory Council; State Child Death Review; Commission for Perinatal Care and Prevention of Infant Mortality; Behavioral Health Planning Council; Early Care and Education Council; Developmental Disabilities Council; State Inter-agency Planning Council (IDEA Part C); Birth Defects Monitoring Network Advisory Board; Reproductive Health Advisory Board • Louisiana Hospital Association (LHA) • Louisiana Chapter of the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)
Hospitals	• 52 Birthing hospitals statewide • Children's Hospital of New Orleans, LA
Public Health Agencies and Universities	• Louisiana Public Health Institute (LPHI) • Southeast and Southwest Louisiana Area Health Education Centers • Agenda for Children • Prevent Child Abuse Louisiana (PCAL) • Louisiana Foundation Against Sexual Assault (LaFASA) • Tulane University School of Public Health's Global Community and Behavioral Health Sciences Department, Mary Amelia Women's Center and MCH Leadership Training Program; Tulane School of Medicine

BFH and CYSHCN Programs' Partners	
Level	**Partners**
Public Health Agencies and Universities	• LSU Schools of Public Health and School of Medicine (including the Pediatric Department), Human Development Center, School of Nursing, School of Dentistry, and Agricultural Center • Loyola University Fatherhood Consortium • Xavier University • Dillard University's Environmental Justice Program • University of Louisiana at Lafayette – Cecil J. Picard Center for Child Development and Lifelong Learning • University of Louisiana at Monroe • Pennington Biomedical Research Center
Community	• Healthy Start Programs (New Orleans, Lafayette, Baton Rouge) • People's Institute for Survival and Beyond • Institute for Women and Ethnic Studies • Tulane University Adolescent Drop-In Center • Baptist Community Ministries • New Orleans Fatherhood Consortium 64 Parish Coroners' offices • Child care centers statewide • Local school districts statewide • Local entities contracting with BFH and CYSCHN Programs for services
Families	• Families Helping Families (FHF) centers statewide • CSHS regional clinics' patients and parents • Family Resource Center (FRC) • FRC Advisory Board • MIECHV clients • Reproductive Health clinic patients

Historically, BFH has recognized the critical value of family/consumer partnerships. Consumers and stakeholders are continuously involved in the development and testing of health communication messages and media materials. BFH's Home Visiting and Reproductive Health programs are working together to develop local forums for parents to participate in meaningful conversations about BFH services, issues that matter the most to their families, and ways to strengthen families by building protective factors and reducing risk. BFH is also planning to reconfigure the Regional Community Action Teams (CAT) to assure family/consumer representation on each of these teams. Furthermore, the newly hired State MCH Coordinator is tasked with creating a structured plan to routinely engage families in innovative and creative formats to obtain their insights on current and future activities. BFH leadership is committed to institutionalizing public engagement as a priority and has begun to explore mechanisms that systematically capture both the quantity and quality of relationships with engaged partners.

In light of needs assessment findings, CYSHCN Programs will continue to strengthen family and consumer partnerships and to employ parent and youth liaisons. The coming year's quarterly trainings will prepare parent liaisons to educate CYSHCN caregivers on the importance of developmental screening milestones, ADHD, and ASD screenings.

CSHS will provide Families Helping Families with educational materials for caregivers regarding developmental screening. The CSHS FRC Advisory Board will continue to guide FRC services with strong family representation.