

2020

Title V

Maternal and Child Health Services Block Grant

Comprehensive Needs Assessment

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Executive Summary

I. Introduction

The Title V Maternal and Child Health (MCH) Block Grant Program is a federal-state partnership that is a key source of support for promoting and improving the health and well-being of the nation's women, adolescents, infants, and children, including children and youth with special health care needs (CYSHCN). Authorized under Title V of the 1935 federal Social Security Act, Title V was converted to a Block Grant Program in 1981. State funding allocations are determined by a formula that takes into consideration the proportion of the number of low-income children in a state compared to the total number of low-income children in the United States.

The Title V MCH Block Grant Program requires that every \$4 of federal Title V MCH Block Grant money be matched by at least \$3 of state and/or local money. The program also requires that a minimum of 30% of federal Title V MCH Block Grant funds be used to support services for CYSHCN and 30% of federal funds be used to provide preventive and primary care services for children. In addition to annual performance reporting, states must conduct a comprehensive needs assessment every five years to identify priority issues of the MCH population (<http://www.mchb.hrsa.gov/>).

CYSHCN “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). In Alabama, 22.4% of children and youth ages 0-17 have a special health care need, higher than the national percentage (18.5%). Based on these estimates, 245,036 children and youth in Alabama have a special health care need (www.childhealthdata.org/browse/survey). CYSHCN and their families often need services from multiple systems – health care, public health, education, mental health, and social services.

The Title V MCH Block Grant Needs Assessment is a systematic process to collect information about the state's public health system and service provision to pregnant women, mothers, infants, children, adolescents, and CYSHCN. The information collected through the needs assessment is used to identify statewide priorities, drive strategic planning, and allocate funds. The goal of the statewide needs assessment is to improve MCH outcomes by aligning evidence-based strategies with the identified needs of the MCH population.

II. 2020 Needs Assessment Process

The administration of Alabama's Title V Block Grant is unique in that the Alabama Department of Public Health (ADPH) Bureau of Family Health Services (BFHS) oversees four of the five MCH population domains. These are the Perinatal/Infant, Child, Adolescent, and Women/Maternal Domains. The Children's Rehabilitation Service (CRS), a division of the Alabama Department of Rehabilitation Services (ADRS), oversees the fifth domain, CYSHCN. The needs assessment data collection and prioritization processes were undertaken separately. The final needs assessment and Block Grant submission, however, incorporates the information from both processes into one document.

Promoting health equity and reducing health disparities are guiding principles for both ADPH and CRS. Both agencies seek to operationalize their programs through the lens of health equity as defined in the Healthy People 2020 framework: "...the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities." Furthermore, ADPH and CRS recognize that disparities and inequities are driven by many factors, including social determinants of health such as education, poverty, structural racism, and housing safety and quality. As such, the Title V MCH Needs Assessment included strategies to assure equitable opportunities for participation so that broad stakeholder voices could be heard. These included:

- Fielding paper and mobile-friendly online surveys
- Assuring accessibility of online surveys for screen reading software
- Using translation and interpreter services (surveys and focus groups; Spanish and American Sign Language)
- Partnering with local, trusted organizations for recruitment and awareness efforts
- Facilitating diverse focus groups that included representation based on geography, race, ethnicity, language, income, age, sexual orientation, and disability status
- Providing incentives for focus group participation

Several areas of disparity were identified across all domains. The full domain reports for each population of interest provide more in-depth discussion of identified disparities and inequities.

The needs assessment data collection and prioritization process for each domain is described below.

A. Process for Perinatal/Infant, Child, Adolescent, and Women/Maternal Domains

As part of the 2020 Title V MCH Needs Assessment, the ADPH BFHS entered into an agreement with the University of Alabama at Birmingham (UAB) School of Public Health, Department of Health Care Organization and Policy, Applied Evaluation and Assessment Collaborative (AEAC) to develop, analyze, and report on data collected from Alabama families, service providers, and other stakeholders. Initial exploration and discussion of data collection methods began in spring of 2019, and all data collection instruments were designed through a joint effort between the AEAC and the BFHS. The BFHS was responsible for marketing efforts related to the needs assessment and recruitment across all data collection methods. They coordinated with health departments across the state to engage survey

participants and partnered with the Alabama Network of Family Resource Centers (ANFRC) for recruitment of focus group participants. Key informant interview participants were identified by the BFHS. To ensure successful engagement of participants, the ADPH Title V team facilitated communication between informants and the AEAC. The AEAC built the surveys, facilitated focus groups and key informant interviews, performed all analyses, and developed final reports.

B. Needs Assessment Data Sources and Methods of Collection: Perinatal/Infant, Child, Adolescent, and Women/Maternal Domains

Overview

The data described in this report were collected specifically to capture the experiences and perceptions of stakeholders including health care consumers, families, teens/young adults, and service providers across the state to bolster the BFHS's knowledge and assist in identifying MCH needs. Information compiled from national surveys, census data, vital statistics, and previous needs assessments were considered by the BFHS and are reported elsewhere. All methods were based on previous instruments, past experiences, best practice in instrument development and data collection, and areas of interest by an internal needs assessment leadership team at ADPH. To ensure complete representation of MCH stakeholders across the state, the internal team also identified populations for recruitment.

Federally Available Data

The AEAC used the Federally Available Data (FAD) provided by the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB) through the Title V Information System. ADPH's MCH Epi Branch staff further organized this information by MCH population domain to facilitate use. FAD catalogues the National Performance Measures (NPMs) and National Outcome Measures (NOMs) for each state and jurisdiction. FAD are designed to clarify indicators and aid states in making comparisons between national and state data. Values represent the most recently available data retrieved from

<https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures> and <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures> and the Federally Available Data (FAD) Resource Document (Maternal and Child Health Bureau. Federally Available Data (FAD) Resource Document. July 2, 2020; Rockville, MD: Health Resources and Services Administration. Available at:

<https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>). For the child and adolescent domains, the AEAC accessed the original data source for FAD for these measures (National Survey of Children's Health, www.childhealthdata.org) to stratify data to represent specific age groups.

Surveys

Family Survey - The BFHS conducted a family survey of Alabama residents to obtain information regarding Alabama's capacity and the strengths and weaknesses in the state's health care delivery system. AEAC designed the survey to capture perspectives of Alabama residents, including women of childbearing age and those who are raising children and youth. The survey was disseminated in online and paper versions in both English and Spanish. Surveys were also available in mobile-friendly layouts and screen reader compliant formats. The BFHS sent surveys to all 66 county health departments, and

completed surveys were then returned to the AEAC through the BFHS. The online survey was disseminated through the platform Qualtrics and marketed by the ADPH Title V team to Alabama residents through flyers, social media and website postings, email, and partnerships with other agencies. Data from the paper surveys were entered into Qualtrics and merged with the online version for final analysis. There were a total of 874 survey respondents representing 66 of the 67 Alabama counties.

Provider Survey - The BFHS also conducted a survey of primary health care service providers for women of childbearing age, children, and youth regarding Alabama's service capacity and the state's health care delivery system. The survey was designed by the AEAC and disseminated through Qualtrics. The BFHS marketed the survey through email, social media and website postings, and partnerships with other agencies and health care service providers. There were a total of 119 survey respondents from 36 of Alabama's 67 counties representing the specialties of Family Medicine, Obstetrics and Gynecology, Gynecology, Pediatrics, and Adolescent Medicine. Hospitalists, multi-specialty service providers, and other Allied Health Professionals were also represented in the sample.

Adolescent Survey - For the first time in an Alabama Title V Needs Assessment, the BFHS conducted a survey of adolescents and young adults in Alabama to understand the unique concerns, experiences, and perspectives of this age category. The survey was designed by the AEAC and disseminated through Qualtrics. The BFHS marketed the survey through email, social media and website postings, and partnership with other agencies and health care service providers. There were a total of 86 survey respondents ranging between the ages of 12 and 26.

Key Informant Interviews

Qualitative data collection included semi-structured key informant interviews facilitated with individuals identified by the BFHS as having expert knowledge of one or more MCH populations or about specific issues important to the MCH population in the state. Twenty-two individuals representing local, state, public, and private groups consented to participate in an interview. Interviews were conducted over the phone by AEAC faculty, staff, or graduate trainees. AEAC staff members designed a template for a consistent notetaking process across all team members facilitating interviews. Notes were compared and data were collated by an AEAC staff member for emerging themes; subsequent thematic summaries were determined based on data included in the emerging themes. Strengths, barriers, and gaps/areas of need were also identified from all participants and merged to identify cross agency perceptions. The AEAC team convened to discuss collated data and determine agreement across all team members after completion of the analysis.

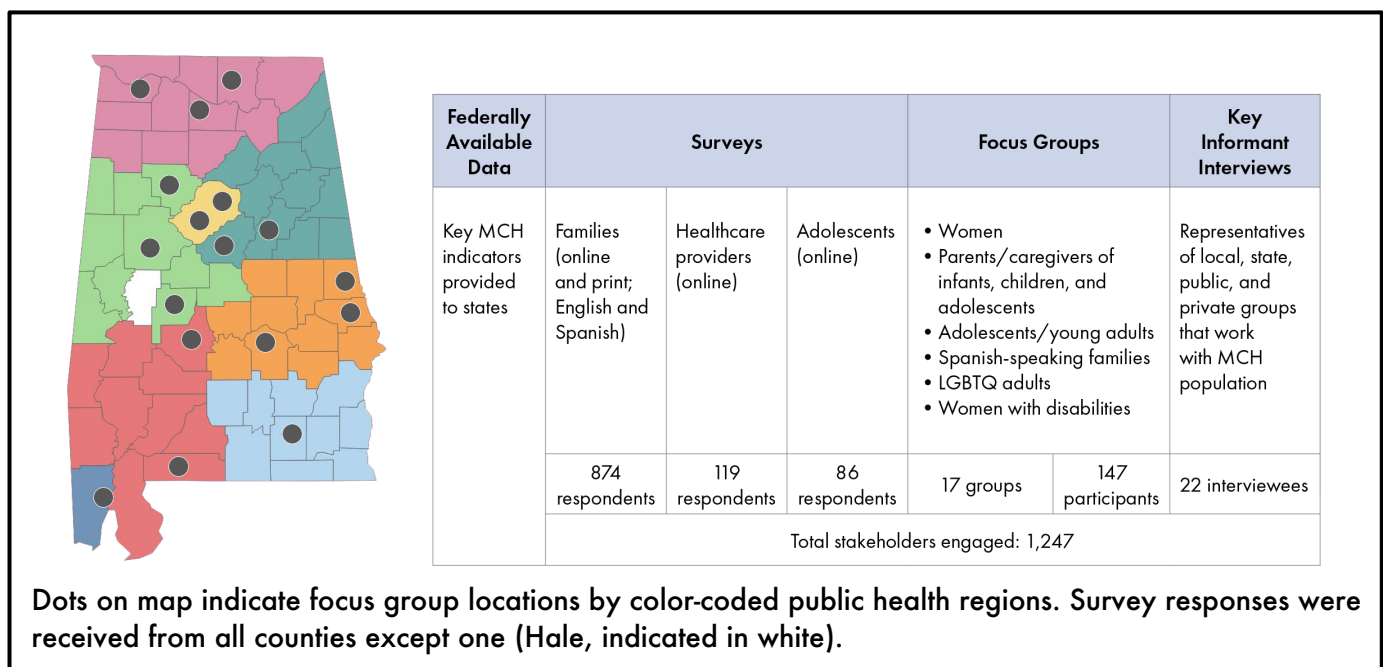
Focus Groups

The BFHS and AEAC partnered with ANFRCs across the state for focus group recruitment. Focus groups were facilitated at ANFRC sites by AEAC staff, faculty, or graduate trainees with community members across Alabama. Each focus group participant was provided incentives including an honorarium and food through an agreement between AEAC and ANFRC. Focus group participants included women; parents/caregivers of infants, children, and adolescents; adolescents/young adults; Spanish-speaking families; LGBTQ adults; and women with disabilities. A total of 147 participants attended 17 focus groups in 16 of Alabama's 67 counties, representing areas in north, central, and south Alabama. All focus groups were recorded and professionally transcribed.

Two AEAC staff members, designated as coders, analyzed focus group transcripts using the qualitative data analysis software NVivo. To facilitate the process, existing codes were used from the 2015 ADPH Needs Assessment analysis to develop the initial codebook for the 2020 process. Subsequent updates to the codebook were documented throughout the process. Coders consulted and discussed final themes and sub-themes for intercoder agreement. A document was created describing the final themes/sub-themes identified.

Figure 1 provides an overview of data collected across all methods focusing on the Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains. A total of 1,247 stakeholders were engaged through surveys, focus groups, and key informant interviews. Socio-demographic characteristics of focus group participants and family and adolescent survey respondents generally matched those for the state. Detailed socio-demographic characteristics of stakeholders who participated in these specific data collection methods for the Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains are presented in Appendix 2.

Figure 1. Overview of Data for Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains



C. Process for CYSHCN Domain

As part of the comprehensive 2020 Title V MCH Needs Assessment, the ADRS CRS entered into an agreement with the AEAC to develop, analyze, and report on data collected from Alabama families, service providers, and other stakeholders. Initial exploration, discussion, and design of all data collection instruments was a joint effort between the AEAC and the CRS Title V team. CRS was responsible for marketing efforts related to the needs assessment and recruitment across all data collection methods. The CRS Title V team collaborated with CRS locations across the state for

recruitment of survey participants and helped identify key informants for semi-structured interviews. The CRS Title V team and the AEAC consulted with the CRS Parent Consultants and Family Voices of Alabama for recruitment of focus group participants. The AEAC facilitated the focus groups and key informant interviews, performed all analyses, and developed final reports. The methods used and results obtained are summarized below. An in-depth report of the CYSHCN domain is available through CRS.

D. Needs Assessment Data Sources and Methods of Collection: CYSHCN Domain

Overview

During the Title V MCH Needs Assessment process, CRS leadership and the AEAC were guided by the principles of promoting health equity and reducing health disparities. The data described in this summary were collected specifically to understand the landscape of CYSHCN through national data sources and capture the experiences and perceptions of stakeholders including CYSHCN, families of CYSHCN, and service providers working with the CYSHCN population. The methods were based on previous instruments, past experience, best practice in instrument development and data collection, the Title V MCH Block Grant Needs Assessment guidance, and areas of interest identified by an internal needs assessment leadership team at CRS. Additionally, all data collection tools were designed for accessibility and to encourage participation from a diverse population.

A mixed methods approach was used for data collection, including quantitative and qualitative methods, and data sources were merged to triangulate the national data with the issues and needs identified by community stakeholders across Alabama. These compiled data sources provided a holistic picture of the issues and needs for CYSHCN and their families and led to the development of need statements that were presented to Alabama stakeholders and leadership. Need statements were ranked and prioritized with the community stakeholders and leadership to identify focal points and priority needs for the next five-year cycle.

Federally Available Data

The AEAC again used the FAD provided by HRSA/MCHB through the Title V Information System. Values represent the most recently available data retrieved from

<https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures> and <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures> and the Federally Available Data (FAD) Resource Document (Maternal and Child Health Bureau. Federally Available Data (FAD) Resource Document. July 2, 2020; Rockville, MD: Health Resources and Services Administration. Available at:

<https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>). For the CYSHCN domain, some FAD aligned with this population included both CYSHCN and non-CYSHCN. For these measures, AEAC staff again accessed the original data source (National Survey of Children's Health, www.childhealthdata.org) to stratify the data to limit analyses exclusively to performance for CYSHCN.

Surveys

Family Survey - CRS conducted a family survey of Alabama residents to obtain information regarding Alabama's capacity and the strengths and weaknesses in the state's health care delivery system. AEAC designed the survey to capture perspectives of families/caregivers of CYSHCN. The survey was disseminated in online and paper versions in both English and Spanish. Surveys were also available in mobile-friendly layouts and screen reader compliant formats. CRS sent surveys to all CRS offices across the state, and completed surveys were then returned to the AEAC through CRS. The online survey was disseminated through the platform Qualtrics and marketed by the CRS Title V team to families/caregivers of CYSHCN through flyers, social media and website postings, email, and partnerships with other agencies. Data from the paper surveys were entered into Qualtrics and merged with the online version for final analysis. There were a total of 416 family survey respondents.

Youth Survey - CRS also conducted a survey of youth and young adults with SHCN in Alabama. The survey was designed by the AEAC and disseminated through Qualtrics. CRS marketed the survey through email, social media and website postings, and partnerships with other agencies. This survey was disseminated in both online and paper formats, in English only, and was available to youth and young adults between the ages of 13 and 25. Data from the paper surveys were entered into Qualtrics and merged with the online version for final analysis. There were a total of 147 youth survey respondents.

Key Informant Interviews

Qualitative data collection included semi-structured key informant interviews facilitated with individuals identified by CRS as having expert knowledge of CYSHCN and the systems of care that serve this population. Seventeen individuals representing local, state, public, and private groups consented to participate in an interview. Interviews were conducted over the phone by AEAC faculty, staff, or graduate trainees with various service providers and educators of CYSHCN, youth, and individuals representing the Spanish-speaking community. AEAC staff members designed a template for a consistent notetaking process across all team members facilitating interviews. Notes were compared and data were collated by an AEAC staff member for emerging themes; subsequent thematic summaries were determined based on data included in the emerging themes. Strengths, barriers, and gaps/areas of need were also identified from all participants and merged to identify cross agency perceptions. The AEAC team convened to discuss collated data and determine agreement across all team members after completion of the analysis.

Focus Groups

Focus group participants were intentionally recruited in urban and rural areas. CRS and the AEAC engaged partners who were trusted members of the communities they served to host and recruit participants. These partners made accommodations to support physical access to locations and ensure that focus groups were facilitated in the participants' primary language. Additionally, each focus group participant was provided incentives including an honorarium, food, childcare, and/or transportation support through an agreement between CRS and Family Voices of Alabama.

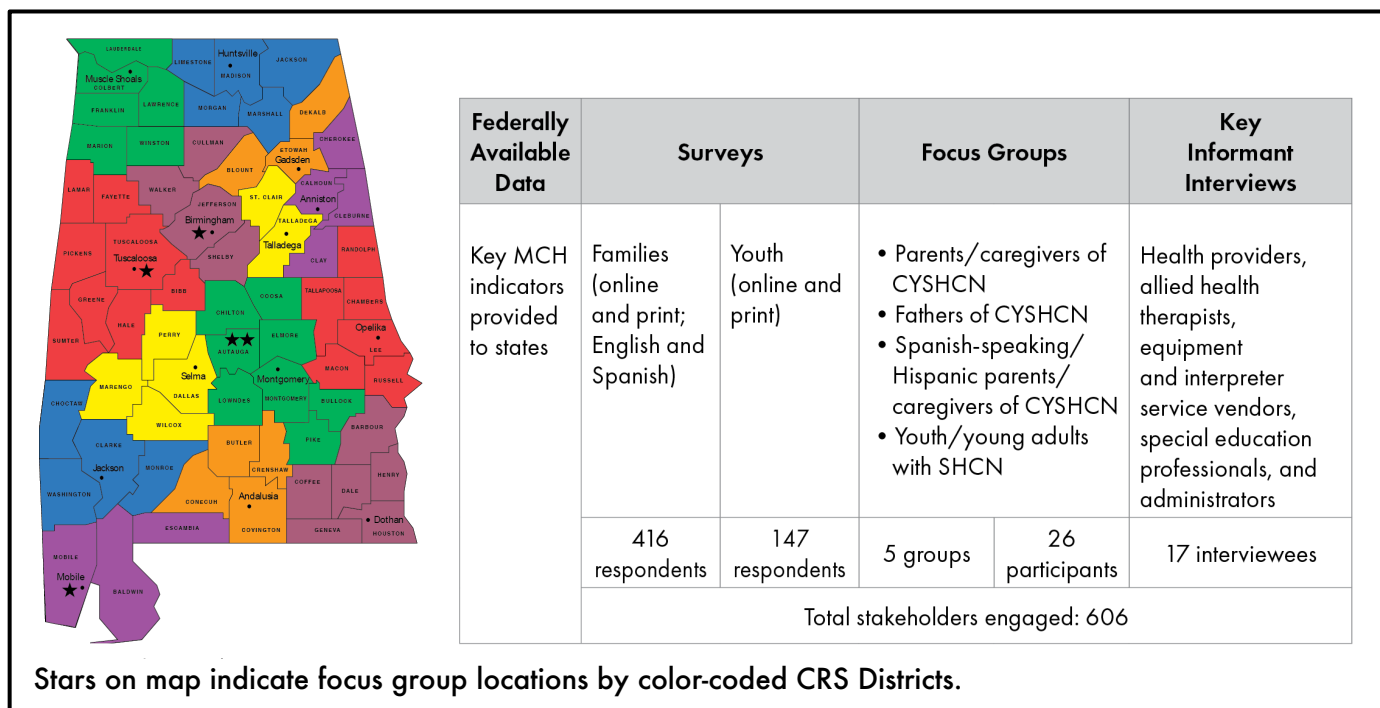
CRS and the AEAC collaborated with Family Voices of Alabama for focus group recruitment and assistance with the logistics of locations and incentives. Five focus groups were facilitated by AEAC staff, faculty, or graduate trainees in four locations: Mobile, Birmingham, Prattville, and Tuscaloosa.

Focus group participants included caregivers of CYSHCN, fathers of CYSHCN, Spanish speaking caregivers of CYSHCN, and youth/young adults with SHCN. A total of 26 participants attended five focus groups representing areas in west, central, and south Alabama. All focus groups were recorded and professionally transcribed.

Two AEAC staff members, designated as coders, analyzed focus group transcripts using the qualitative data analysis software NVivo. To facilitate the process, existing codes were used from the 2015 CRS Needs Assessment analysis to develop the initial codebook for the 2020 process. Subsequent updates to the codebook were documented throughout the process. Coders consulted and discussed final themes and sub-themes for intercoder agreement. A document was created describing the final themes/sub-themes identified.

Figure 2 provides an overview of data collected across all methods focusing on CYSHCN and their families. A total of 606 stakeholders were engaged through surveys, focus groups, and key informant interviews. Socio-demographic characteristics of focus group participants and family and youth survey respondents generally matched those for the state. Detailed socio-demographic characteristics of stakeholders who participated in these specific data collection methods for the CYSHCN Domain are presented in Appendix 3.

Figure 2. Overview of Data for CYSHCN Domain



III. Findings by MCH Population Domain

Overview

Consistent with the mixed-methods process outlined above, the information below incorporates both quantitative and qualitative findings. Each of the following sections begins with an overview of the FAD from the HRSA/MCHB Title V Information System. Data presented include NPMs and NOMs reported for Alabama. These are used to set a baseline quantitative picture of the state. Following the FAD chart in each specific domain are summaries of the major themes drawn from the qualitative data collection strategies. These quantitative and qualitative data led to the development of the need statements that were presented to stakeholders and leadership to choose as the state's priority needs for the coming five-year cycle.

Presented below are the major themes for each Title V MCH population domain. For in-depth descriptions of each theme, please refer to the full domain report for each population of interest.

A. Women/Maternal Domain

Women's/Maternal Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Well-woman visit	66.3%	About the same	About the same
Low-risk cesarean delivery (first births)	28.2%	Worse	Trending better
Preventive dental visit – during pregnancy	40.6%	Worse	About the same
Smoking – during pregnancy	9.6%	Worse	Trending better
Postpartum depression	16.3%	Worse	Trending better
Early prenatal care	71.5%	Worse	About the same
Early elective delivery	1.0%	About the same	Trending better
Teen births	27 per 1,000	Worse	Trending better

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arrears. See page 3 for information on FAD and to access current information.

For the women/maternal domain, seven themes were identified following a thorough consideration of all data collection methods. Full descriptions of these themes may be found in the full women/maternal domain report.

1. Health and Wellness
2. Mental Health
3. Reproductive Health
4. Smoking, Substance, and Alcohol Use
5. Health Care Access, Cost, and Insurance
6. Oral Health Care Access, Cost, and Insurance
7. Maternal Mortality

From these themes, the following women/maternal needs were identified (listed in stakeholder-prioritized order; see discussion beginning on page 19 for a description of the prioritization process):

RANK	Potential Priority Need/Issue
1	High levels of maternal mortality
2	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
3	Inadequate or lack of comprehensive, affordable health and dental insurance
4	Lack of or inadequate access to comprehensive mental health services (prevention, crisis care, postpartum)
5	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services
6	Lack of or inadequate access to comprehensive, family-centered, and culturally competent reproductive and well-woman health care and education, including for LGBTQ populations and women with disabilities
7	Lack of or inadequate access to supports for health and wellness, including education, affordable and safe options for physical activity, and healthy foods
8	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, disability status, insurance status/type, primary language, sexual orientation, and gender identity
9	Insufficient or inadequate translated educational materials and timely interpreter services for individuals whose primary language is not English

B. Perinatal/Infant Domain

Perinatal/Infant Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Risk-appropriate perinatal care – very low birth weight babies born in hospitals with Level III+ NICU	84.1%	NA	Trending better
Breastfeeding – ever	68.1%	Worse	About the same
Breastfeeding – exclusively through 6 months	20.6%	Worse	Trending better
Safe sleep – infant placed on back	71.3%	Worse	About the same
SUID mortality	216.4 per 100,000	Worse	Trending worse
Infant mortality	9.0 per 1,000	Worse	Mixed
Preterm birth	12.0%	Worse	About the same
Low birth weight	10.3%	Worse	About the same
Early elective delivery	1.0%	About the same	Trending better

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in areas. See page 3 for information on FAD and to access current information.

For the perinatal/infant domain, eight themes were identified following a thorough consideration of all data collection methods. Full descriptions of these themes may be found in the full perinatal/infant domain report.

1. Pregnant and Parenting Teens and Young Families/New Parents
2. Safe Sleep Education
3. Breastfeeding
4. Infant Mortality
5. Mental Health
6. Reproductive Health
7. Smoking, Substance, and Alcohol Use
8. Health/Dental Care Access, Cost, and Insurance

From these themes, the following perinatal/infant needs were identified (listed in stakeholder-prioritized order; see discussion beginning on page 19 for a description of the prioritization process):

RANK	Potential Priority Need/Issue
1	High levels of infant mortality (and associated factors of preterm birth and low birth weight)
2	High levels and worsening trends of sleep-related/SUID deaths
3	Inequitable access to health resources (including delivery hospitals) based on race/ethnicity, socioeconomic status, geographic location, and education
4	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services
5 (tie)	Lack of or inadequate access to comprehensive reproductive health care
5 (tie)	Lack of or inadequate comprehensive, affordable health and dental insurance
7	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, insurance status/type, and primary language
8 (tie)	Lack of or inadequate access to breastfeeding supports
8 (tie)	Lack of supports for pregnant and parenting teens and young/new parents
10	Lack of or inadequate access to comprehensive mental health services (prevention, crisis care, postpartum)

C. Child Domain

Child Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Developmental screening (9-35 months)	26.6%	Worse	Trending better
Physical activity (6-11 years, every day)	26.8%	About the same	About the same
Preventive dental visit – child (6-11 years)	91.5%	Better	About the same
Child mortality	24.6 per 100,000	Worse	Trending better
Obesity (2-4 years)	16.3%	Worse	Trending worse
Child vaccination (19-35 months)	71.2%	About the same	Trending better

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arears. See page 3 for information on FAD and to access current information.

For the child domain, five themes were identified following a thorough consideration of all data collection methods. Full descriptions of these themes may be found in the full child domain report.

1. Health and Wellness
2. Pregnant and Parenting Teens and Young Families/New Parents
3. Child Mental Health
4. Health and Oral Health Care Access, Cost, and Insurance
5. Health and Developmental Screening

From these themes, the following child needs were identified (listed in stakeholder-prioritized order; see discussion beginning on page 19 for a description of the prioritization process):

RANK	Potential Priority Need/Issue
1 (tie)	Lack of timely, appropriate, and consistent health and developmental screenings
1 (tie)	Lack of access to quality early childhood programs that are safe and affordable, especially for children with disabilities
3	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
4	High levels and worsening trends for childhood obesity
5	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services

6	Lack of or inadequate smoking, alcohol, and substance use prevention education
7	Lack of or inadequate access to mental health services that are comprehensive and age-appropriate
8	Lack of comprehensive, family-centered, and culturally competent health care
9	Lack of supports for pregnant and parenting teens and young/new parents

D. Adolescent Domain

Adolescent Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Physical activity (12-17 years, every day)	20.6%	Better	Trending worse
Bullying (victimization)	19.6%	About the same	About the same
Adolescent well-visit	76.3%	About the same	About the same
Preventive dental visit – adolescent	88.0%	Better	About the same
Adolescent mortality	46.9 per 100,000	Worse	About the same
Adolescent motor vehicle death	25 per 100,000	Worse	Trending better
Adolescent suicide	9.1 per 100,000	Better	Trending worse
HPV vaccination	58.0%	Worse	Trending better
Obesity – ages 10-17	18.2%	Worse	Trending worse
Teen births	27.0 per 1,000	Worse	Trending better

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arears. See page 3 for information on FAD and to access current information.

For the adolescent domain, six themes were identified following a thorough consideration of all data collection methods. Full descriptions of these themes may be found in the full adolescent domain report.

1. Pregnant and Parenting Teens
2. Reproductive and Sexual Health Education
3. Adolescent Mental Health
4. Adolescent Smoking, Substance, and Alcohol Use
5. Physical Activity
6. Need for Trusted Adult Role Models and Mentors

From these themes, the following adolescent needs were identified (listed in stakeholder-prioritized order; see discussion beginning on page 19 for a description of the prioritization process):

RANK	Potential Priority Need/Issue
1	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
2	Lack of or inadequate access to mental health services that are comprehensive and age-appropriate
3	Lack of supports for pregnant and parenting teens
4	Lack of or inadequate substance abuse treatment (smoking, alcohol, drugs) and prevention education
5	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, insurance status/type, sexual orientation, and gender identity
6	Inadequate and insufficient health and sexual health education
7	Lack of or inadequate access to comprehensive reproductive health care, including for LGBTQ populations and adolescents with disabilities
8	Inadequate or insufficient preparation, information, and resources to support transition to adulthood
9	Lack of or inadequate access to affordable and safe options for physical activity, exercise, and recreation
10	Limited access to adult role models and mentors

E. CYSHCN Domain

CYSHCN Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Medical home	37.0%	Slightly worse	Trending slightly worse
Transition**	15.0%	Slightly worse	Trending slightly better
Adequate insurance	64.2%	Slightly better	Trending slightly worse
CYSHCN systems of care (received all components of a well-functioning system: family partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition)	16.3%	Slightly better	Trending slightly worse

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arrears. See pages 3 and 6 for information on FAD and to access current information.

**Data may be unreliable due to small sample

For the CYSHCN domain, 14 themes were identified following a thorough consideration of all data collection methods. Full descriptions of these themes may be found in the full CYSHCN domain report.

1. Limited Access to Care and Quality of Services
2. Lack of Transportation
3. Difficulty Finding Convenient and Qualified Service Providers
4. Inadequate Insurance Coverage and Cost
5. Strict Program Qualifications
6. Limited Access to Community-Based Services
7. Inconsistent Accessibility and Accommodations
8. Safe, Affordable, and Inclusive Child Care and Preschool Programs
9. Transition to Adulthood and Adult Health Care (includes the following sub-themes):
10. Inaccessibility of Family Supports and Respite Care
11. Special Education
12. Navigation of Complex Systems of Care
13. Challenges Related to Technology, Electronic Medical Records, and Lack of Data
14. Healthy (and Less Healthy) Behaviors for CYSHCN

From these themes, the following CYSHCN needs were identified (listed in stakeholder-prioritized order; see discussion beginning on page 22 for a description of the prioritization process):

RANK	Potential Priority Need/Issue
1	Insufficient special education services
2	Lack of or inadequate access to health and related services, especially in rural areas and for services identified as difficult to obtain
3	Inadequate insurance, including cost and benefit coverage issues
4	Lack of or inadequate supports for transition to all aspects of adulthood
5 (tie)	Lack of or inadequate access to comprehensive medical homes
5 (tie)	Lack of or inadequate transportation for accessing health and community services
7	Support shared decision-making and partnerships between families and health-related professionals
8	Increase family and youth involvement and participation in advisory groups, program development, policymaking, and system-building activities
9	Lack of provider workforce that is knowledgeable about CYSHCN, especially in rural areas and for adult services
10 (tie)	Lack of or inadequate access to community services and supports, especially in rural areas and for services identified as difficult to obtain
10 (tie)	Lack of access to quality early childhood programs that are safe and affordable, especially for children with disabilities
12	Lack of or inadequate accessibility and accommodation supports, including physical environment, interpreter services, and materials
13	Lack of integrated technology, medical records, and data to support continuity of care and data-informed decision-making for program planning and evaluation
14	Youth with SHCN are not meeting guidelines for physical activity and nutrition
15	Inadequate assistance for families – especially those who are new to the state, whose first language is not English, and who have a child with a new diagnosis – to navigate the system of care, including identifying providers, family supports, and community resources

IV. Description of Prioritization Processes

A. Need Prioritization for Perinatal/Infant, Child, Adolescent, and Women/Maternal Domains

Final selection of priority needs was done in a two-phase process. It was a priority of the BFHS to include broad stakeholder input on the developed need statements prior to making any decisions. Following stakeholder input, BFHS leadership was informed by stakeholder opinions while incorporating their knowledge of agency capacity and other feasibility considerations.

Phase 1: Stakeholder Input

In early March 2020, ADPH convened four half-day, domain-specific meetings of key constituents and consumers to serve as an advisory committee and to assist with the prioritization of identified MCH needs. The total number of meeting participants by domain was:

Women/Maternal = 58
Perinatal/Infant = 57
Child = 40
Adolescent = 30

Each session included an overview of Title V and the needs assessment process. The FAD related to the domain was shared along with summaries of the qualitative data collected from the community. In each session, the domain's list of needs was presented for consideration, and participants were divided into small groups for discussion and individual rating.

Process to Obtain Rankings of Needs for Each Domain

Participants were asked to rate each need according to the following three criteria:

1. *Importance based on data and impact on population*
2. *Alignment with other priorities and initiatives within Alabama*
3. *Existence of effective interventions or potential solutions*

Individual ratings for criteria scores were summed to yield a total score for each need and assign rank order for needs. Below is a description and chart showing the specific considerations for each of the three criteria:

1. *Importance for community/population based on data*: The extent or scope based on all data; how important is this issue or need based on what you have heard from the data presentation?

Rating Scale for Importance

1 = Low Importance	2 = Low-Medium Importance	3 = Medium Importance	4 = Medium-High Importance	5 = High Importance
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2. *Aligns with other priorities and initiatives in Alabama*: The extent to which the issue/need aligns with other priorities and initiatives in Alabama

Rating Scale for Alignment

1 = No/Low Alignment	2 = Low-Medium Alignment	3 = Medium Alignment	4 = Medium-High Alignment	5 = High Alignment
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3. *Effective interventions or potential solutions*: The extent to which evidence-based or evidence-informed solutions and interventions exist to address the issue or need

Rating Scale for Effective Interventions

1 = No interventions or solutions exist	2 = Few interventions or solutions exist	3 = Some interventions or solutions exist	4 = Many interventions or solutions exist	5 = Extensive interventions or solutions exist
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Individual ratings for criteria scores were summed to yield a total score for each need. Total scores were summed for entire group to assign rank order for needs.

Phase 2: Leadership Rating and Final Decisions

Following the rating and final rankings that the broader stakeholders completed at the March 2020 meetings, the BFHS Management Team convened (via webinar and online survey, in response to the ongoing COVID-19 pandemic) to reach consensus on the final priority needs identified in the 2020 Needs Assessment Process. This team rated all priority needs in their domains of focus on five criteria (described below). The average of these scores were then calculated. If the priority need was rated in the top three on the community stakeholder rankings from Phase 1, it received an additional point.

Below are the criteria, special considerations for ranking, and ranking system.

1. *Aligns with other priorities and initiatives in organization and/or state*
2. *Feasibility*
3. *Measure/method to assess*
4. *Opportunities to collaborate with other national, state, and/or community partners*
5. *Health/outcome equity and disparities*

Individual ratings for criteria scores were averaged to yield a total score for each need to assign rank order for needs. Those needs that rated in the top three in the rankings from Phase 1 had an additional point added to the average. Below is a description and chart showing the specific considerations for each of the five criteria:

1. *Aligns with other priorities and initiatives in organization and/or state*: The extent to which the need aligns with other priorities/initiatives in the state and/or the ADPH

Rating Scale for Alignment

1 = Low Alignment	2 = Moderate Alignment	3 = High Alignment
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2. *Feasibility*: The extent to which addressing the need is feasible based on cost, expertise, time, resources, political will, and existence of evidence-based solutions

Rating Scale for Feasibility

1 = Low Feasibility	2 = Moderate Feasibility	3 = High Feasibility
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3. *Measure/Method to assess*: The extent to which data and/or measurement strategy exists (or willingness/ability to develop exists) to monitor progress on addressing the need

Rating Scale for Measure

1 = No measure exists and agency not willing or unable to develop	2 = Measure doesn't exist, but agency is willing and able to develop	3 = Measure exists
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4. *Opportunities to collaborate with other national, state, and/or community partners:* The extent to which addressing this need offers opportunities to collaborate with others at national, state, and/or community levels

Rating Scale for Collaboration

1 = Low Potential for Collaboration	2 = Moderate Potential for Collaboration	3 = High Potential for Collaboration
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5. *Health/outcome equity and disparities:* The extent to which the need is associated with inequitable attainment of highest level of health-related outcomes; the extent of disparities in outcome for some population groups

Rating Scale for Equity

1 = No/minimal inequity or disparity exists	2 = Moderate inequity or disparity exists	3 = Significant equity or disparity exists
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B. Need Prioritization for the CYSHCN Domain

Impacts of COVID-19 led to changes in the original design for the need statement prioritization process. Final selection of priority needs was done in a two-phase process. CRS aimed to prioritize inclusion of broad stakeholder input on the developed need statements prior to making final decisions of the priority needs. Following stakeholder input, a meeting was held with CRS leadership to discuss stakeholder opinions and incorporate their knowledge of agency capacity and other feasibility considerations in their final choice of priority needs.

Phase 1: Stakeholder Input

Due to the COVID-19 pandemic, the scheduled in-person advisory committee meeting for stakeholder engagement with the prioritization process was canceled. The AEAC worked with CRS to develop an online format for presentation of findings and prioritization, including recorded YouTube video presentations embedded within a Qualtrics survey. Over three days in April 2020, CRS and the AEAC made available an asynchronous online portal for the advisory committee to view findings, provide input, and rate needs to assist with the prioritization of the 15 identified needs for CYSHCN. Each stakeholder registered to participate and received a link to the portal. The portal included short presentations to provide an overview of Title V and the needs assessment process, the FAD related to the CYSHCN domain, and the summaries of the qualitative data. Stakeholders could work at their own pace over the three days and, after listening to the short presentations, complete an individual rating for each need according to three criteria. AEAC staff monitored the portal each day to address questions and send participation reminders to advisory committee members.

Participants were asked to rate each need according to the following three criteria:

1. *Importance based on data and impact on population*
2. *Alignment with other priorities and initiatives within Alabama*
3. *Existence of effective interventions or potential solutions*

A total of 37 stakeholders participated in the virtual prioritization process. Individual ratings for criteria scores were summed to yield a total score for each need to assign rank order for needs. Below is a description and chart showing the specific considerations for each of the three criteria:

1. *Importance based on data/Impact on population:* The extent or scope based on all data; how important is this issue or need based on what you have heard from the data presentation? What is the extent of impact for CYSHCN and families if this issue or need were addressed?

Rating Scale for Importance/Impact

1 = Low Importance/ Impact	2 = Low-Medium Importance/ Impact	3 = Medium Importance/ Impact	4 = Medium-High Importance/ Impact	5 = High Importance/ Impact
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2. *Aligns with other priorities and initiatives in Alabama:* The extent to which the issue/need aligns with other priorities and initiatives in Alabama

Rating Scale for Alignment

1 = No/Low Alignment	2 = Low-Medium Alignment	3 = Medium Alignment	4 = Medium-High Alignment	5 = High Alignment
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3. *Effective interventions or potential solutions:* The extent to which evidence-based or evidence-informed solutions and interventions currently exist to address the issue or need

Rating Scale for Effective Interventions

1 = No interventions or solutions exist	2 = Few interventions or solutions exist	3 = Some interventions or solutions exist	4 = Many interventions or solutions exist	5 = Extensive interventions or solutions exist
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Phase 2: Leadership Rating and Final Decisions

Following the rating and final rankings that the broader stakeholders completed during the April 2020 online asynchronous sessions, the CRS leadership team met virtually to reach consensus on the final priority needs identified in the 2020 Needs Assessment Process. CRS leadership discussed each need through the lens of the five criteria described below and reached agreement on a rating based on the scale provided. Additional consideration was given to whether the need was rated in the top three on

the community stakeholder rankings from Phase 1. The top three priority needs for CYSHCN were finalized based on the internal discussion and rating. Below are the criteria, special considerations for ranking, and ranking system.

1. *Aligns with other priorities and initiatives in organization and/or state*
2. *Feasibility*
3. *Measure/method to assess*
4. *Opportunities to collaborate with other national, state, and/or community partners*
5. *Health/outcome equity and disparities*

Below is a description and chart showing the specific considerations for each of the five criteria:

1. *Aligns with other priorities and initiatives in organization and/or state*: The extent or scope based on all data. How important is this issue or need based on what you have heard from the data presentation? What is the extent of impact for CYSHCN and families if this issue or need were addressed?

Rating Scale for Alignment

1 = Low Alignment	2 = Moderate Alignment	3 = High Alignment
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2. *Feasibility*: The extent to which addressing the need is feasible based on cost, expertise, time, resources, political will, existence of evidence-based solutions, and whether addressing the need is within the purview or “control” of CRS

Rating Scale for Feasibility

1 = Low Feasibility	2 = Moderate Feasibility	3 = High Feasibility
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3. *Measure/method to assess*: The extent to which data and/or measurement strategy exists (or willingness/ability to develop exists) to monitor progress on addressing the need

Rating Scale for Measure

1 = No measure exists and agency not willing or unable to develop	2 = Measure doesn't exist, but agency is willing and able to develop	3 = Measure exists
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4. *Opportunities to collaborate with other national, state, and/or community partners:* The extent to which addressing this need offers opportunities to collaborate with others at national, state, and/or community levels

Rating Scale for Collaboration

1 = Low Potential for Collaboration	2 = Moderate Potential for Collaboration	3 = High Potential for Collaboration
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5. *Health/outcome equity and disparities:* The extent to which the need is associated with inequitable attainment of highest level of health-related outcomes; the extent of disparities in outcome for some population groups

Rating Scale for Equity

1 = No/minimal inequity or disparity exists	2 = Moderate inequity or disparity exists	3 = Significant equity or disparity exists
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Selection of Priority Needs for CYSHCN

Using the two-phase approach described above, CRS selected three of the 15 identified needs for alignment with National Performance Measures (NPMs) and State Performance Measures (SPMs), development of objectives and Evidence-based or -informed Strategy Measures (ESMs), and further action planning. The three priority needs are:

- Lack of or inadequate supports for transition to all aspects of adulthood
- Lack of or inadequate access to health and related services, especially in rural areas and for services identified as difficult to obtain
- Increase family and youth involvement and participation in advisory groups, program development, policymaking, and system-building activities

Though the additional 12 identified needs are not included in the final list, CRS leadership maintained that, by addressing the three priority needs, many of these other needs would be addressed directly or indirectly through the comprehensive strategies aligned under the selected NPM and two newly developed SPMs.

These three priority needs were incorporated with those identified by the ADPH Title V team in the final Block Grant and needs assessment submission.

V. Final List of Priority Needs

Following discussion on all of the above criteria and consideration of strategic plans for the next five years of Title V Block Grant activities, the following 10 priority needs were chosen.

Final List of 10 Priority Needs	
1	Lack of or inadequate access to services necessary for CYSHCN to transition to all aspects of adult life
2	Lack of or inadequate access to health-related services, especially in rural areas and for services identified as difficult to obtain
3	Increase family and youth involvement and participation in advisory groups, program development, policymaking, and system building activities
4	High levels of maternal mortality
5	High levels of infant mortality (and associated factors of preterm birth and low birth weight)
6	High levels and worsening trends of sleep-related/SUID deaths
7	Lack of timely, appropriate, and consistent health and developmental screenings
8	Lack of preventive dental visits across all Title V populations, especially for those uninsured
9*	Lack of or inadequate or inequitable access to opportunities to make choices that allow people to live a long, healthy life where they live, learn, work, and play
10	Lack of supports for pregnant and parenting teens

* This priority need was developed based on aggregation of number of needs identified in the needs assessment process. Since this need spans across population domains and allows for partnership and collaboration, activities and future reporting will occur in the MCHB's optional cross-cutting/systems-building domain.

ADPH 2020 Title V Maternal and Child Health Services Block Grant Comprehensive Needs Assessment *Domain Report: Women/Maternal*

I. Setting a Baseline for Women's/Maternal Health in Alabama: A Summary of Federally Available Data

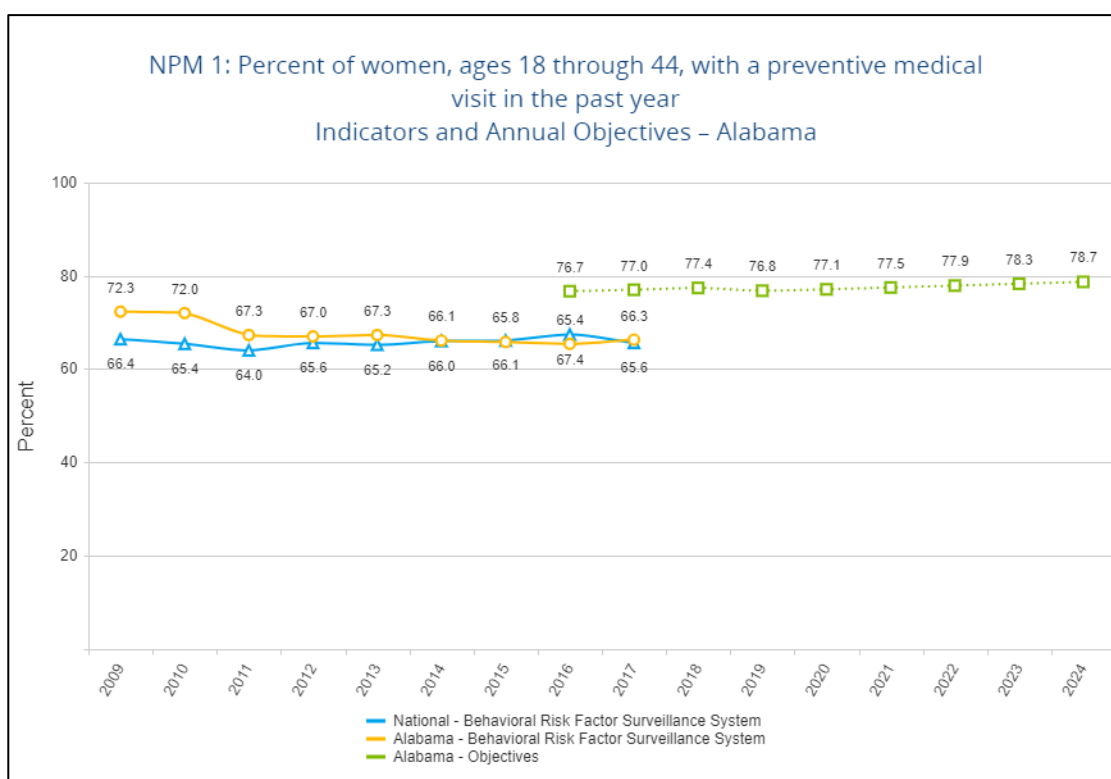
Each state is provided with a set of indicators that cover all Title V domains. These indicators are tied to the National Performance Measures and National Outcome Measures on which states have chosen to focus. The table below summarizes all of the indicators that are associated with women's/maternal health in Alabama.

Women's/Maternal Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Well-woman visit	66.3%	About the same	About the same
Low-risk cesarean delivery (first births)	28.2%	Worse	Trending better
Preventive dental visit – during pregnancy	40.6%	Worse	About the same
Smoking – during pregnancy	9.6%	Worse	Trending better
Postpartum depression	16.3%	Worse	Trending better
Early prenatal care	71.5%	Worse	About the same
Early elective delivery	1.0%	About the same	Trending better
Teen births	27 per 1,000	Worse	Trending better

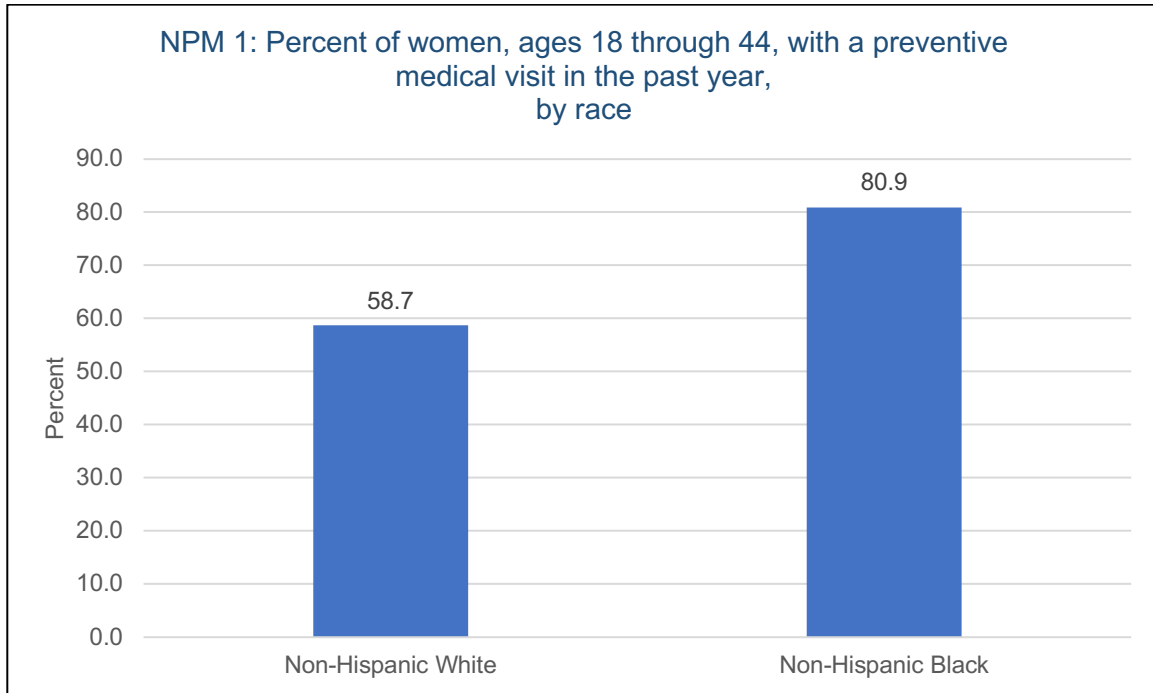
*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arrears. See page 3 for information on FAD and to access current information.

In keeping with the guiding principle of promoting health equity and reducing disparities, several areas of disparity were noted across all domains in both the Federally Available Data (FAD) and qualitative findings. For this domain, indicator data show differences in outcomes based on race, ethnicity, socioeconomic status, education, and insurance status and type. Furthermore, these inequities are driven by many factors, including social determinants of health like education, poverty, structural racism, and housing safety and quality. Notable disparities in sentinel indicators are also presented below in conjunction with the indicators' Alabama-U.S. comparisons.

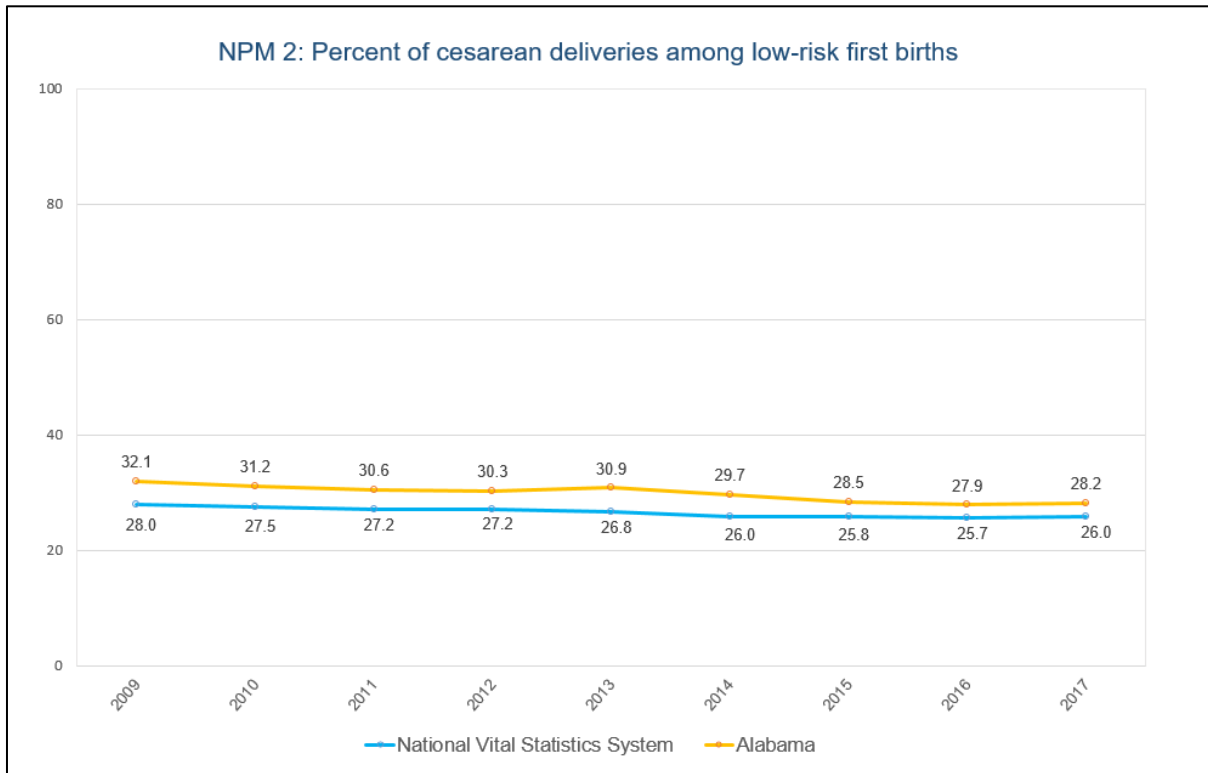
The following charts present the above data in more detailed form and, where available, across time to show comparisons to national indicators and trends.



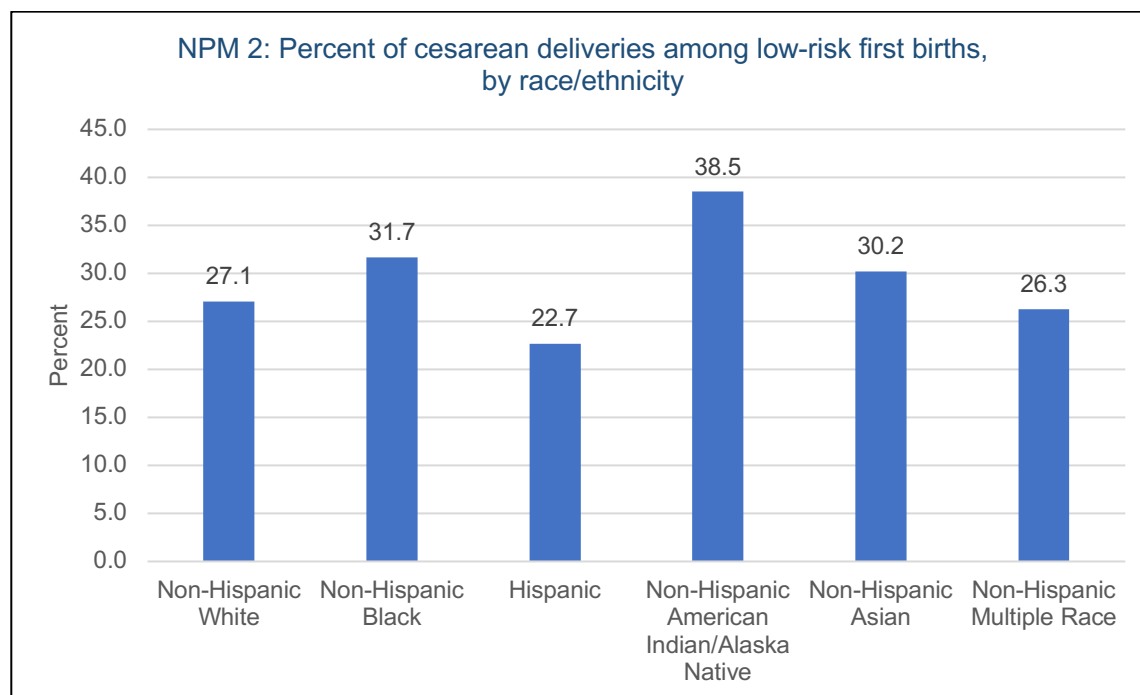
The above data, from the Behavioral Risk Factor Surveillance System, compare Alabama and the U.S. on NPM 1 (Percent of women, ages 18 through 44, with a preventive medical visit in the past year) between 2009 and 2017. In Alabama, the percent has decreased from 72.3% in 2009 to 66.3% in 2017. Nationally, the percent has fluctuated slightly but stayed relatively consistent from 2009 to 2017. In 2009 and 2010, Alabama reported higher percentages than the U.S., though the state now maintains percentages close to the U.S. The green data points indicate the objectives for coming years.



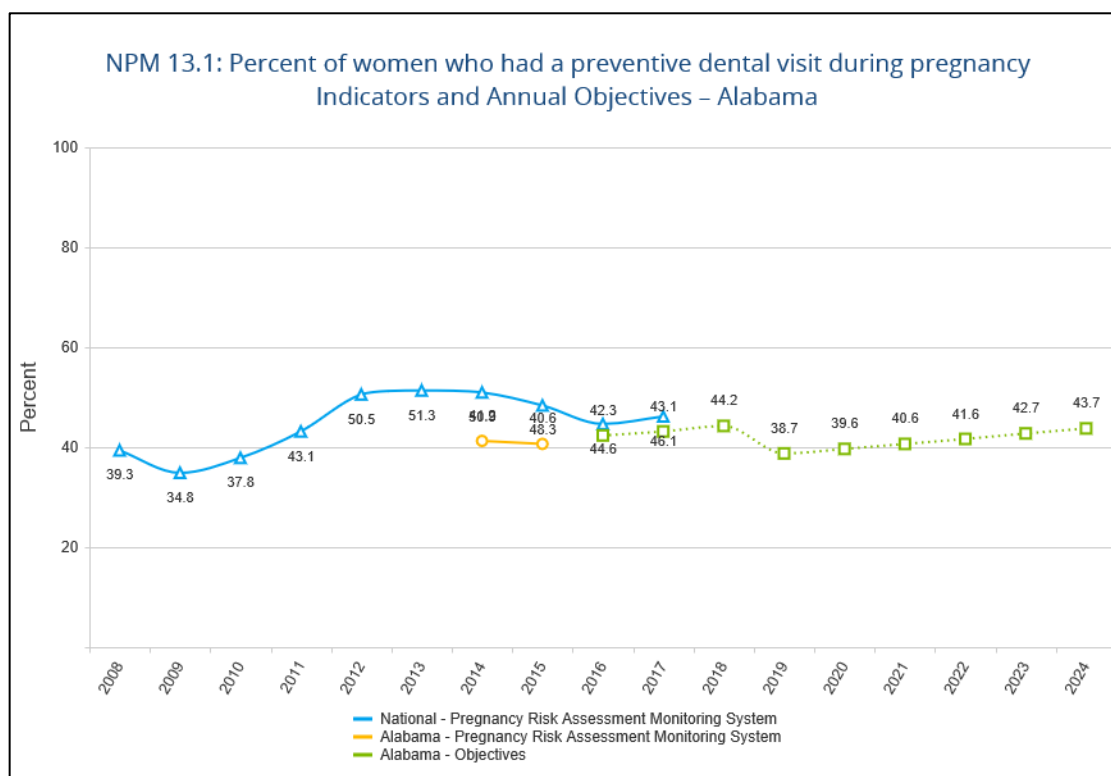
This chart presents the disparities in the percent of women with a preventive medical visit in the past year by race according to the most recent Behavioral Risk Factor Surveillance System data (2017). Non-Hispanic Black women (80.9%) reported a higher percentage of women with a preventive medical visit compared with Non-Hispanic White women (58.7%)



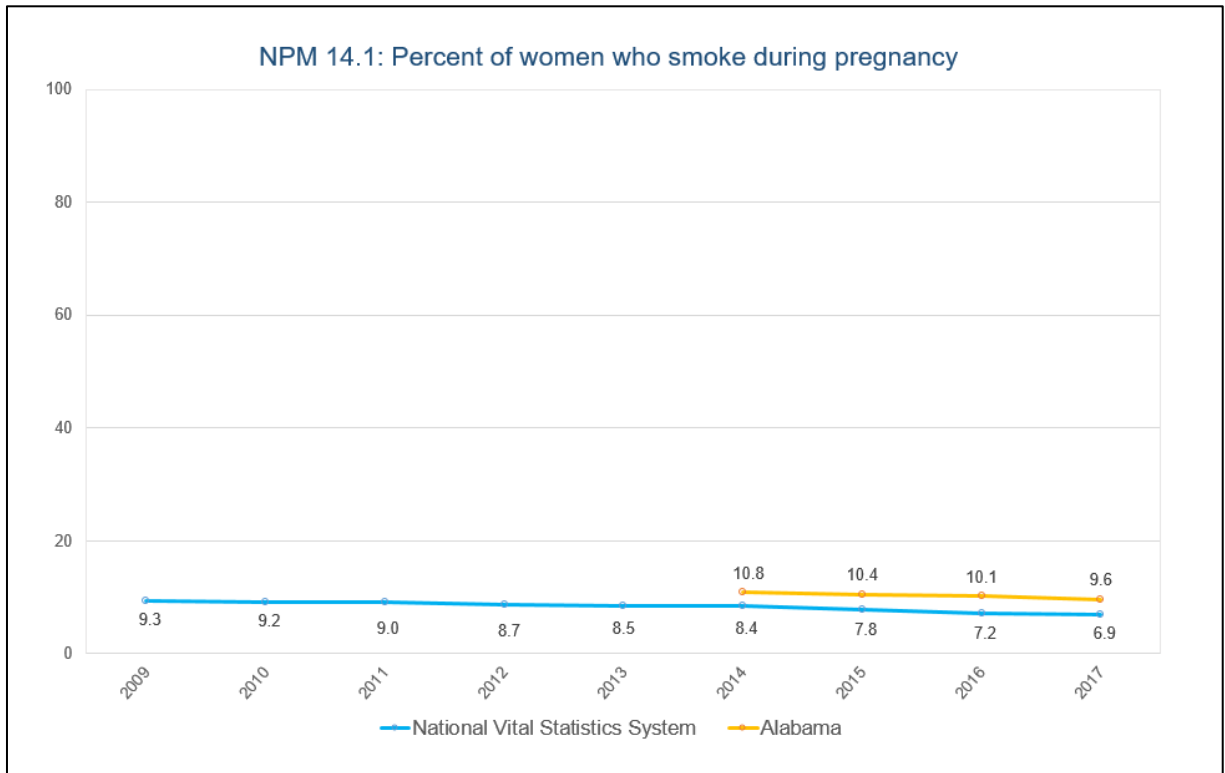
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NPM 2 (Percent of cesarean deliveries among low-risk first births) between 2009 and 2017. For both Alabama and the U.S., the percent has decreased slightly over this period. Alabama consistently reports a slightly higher percent than the U.S., though the difference has narrowed over time.



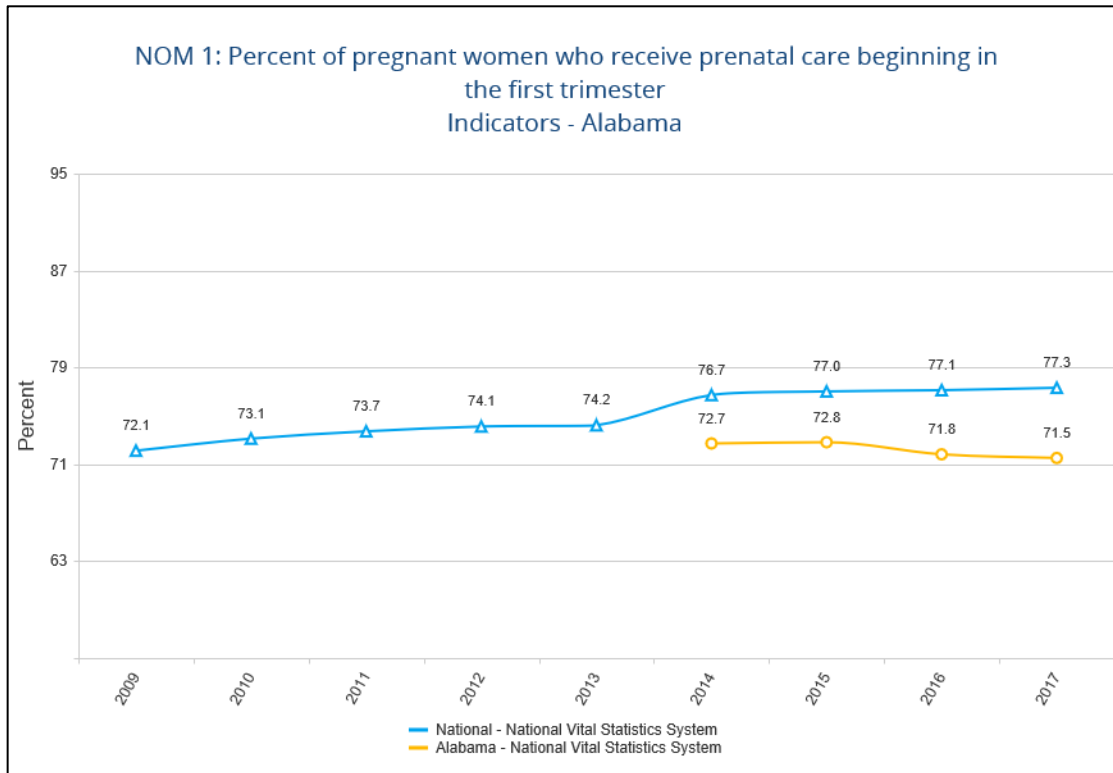
This chart presents the disparities in the percent of cesarean deliveries among low-risk first births by race and ethnicity according to the most recent National Vital Statistics System data (2017). The highest percentage of cesarean deliveries among low-risk first birth was among Non-Hispanic American Indian/Alaska Native women. The lowest percentage of cesarean deliveries was among Hispanic women.



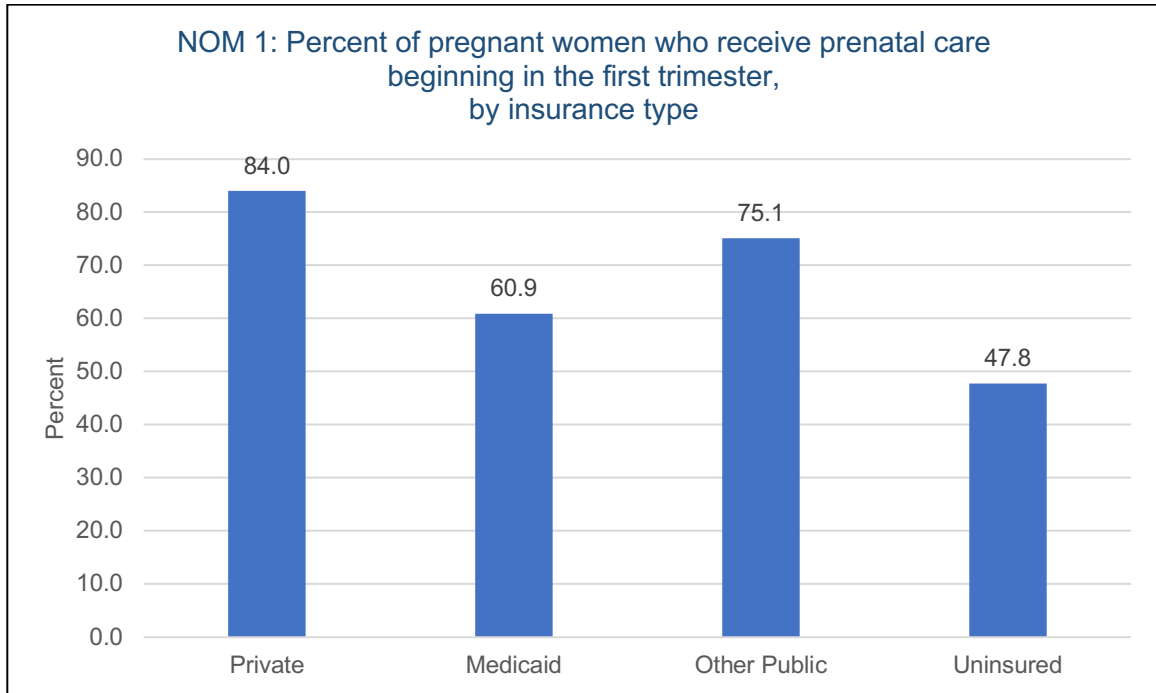
The above data, from the Pregnancy Risk Assessment Monitoring System (PRAMS), compare Alabama and the U.S. on NPM 13.1 (Percent of women who had a preventive dental visit during pregnancy) between 2008 and 2017. Alabama's percent is lower than the U.S., although the state only reported data in 2014 and 2015 (PRAMS data is reported to the Centers for Disease Control and Prevention annually, but only appears in the national dataset if the preset Response Rate Threshold for the year was met by the state). The U.S. percent increased between 2009 and 2013, declining slightly in recent years. Between 2014 and 2015, the percent in Alabama declined slightly. The green data points indicate the objectives for coming years.



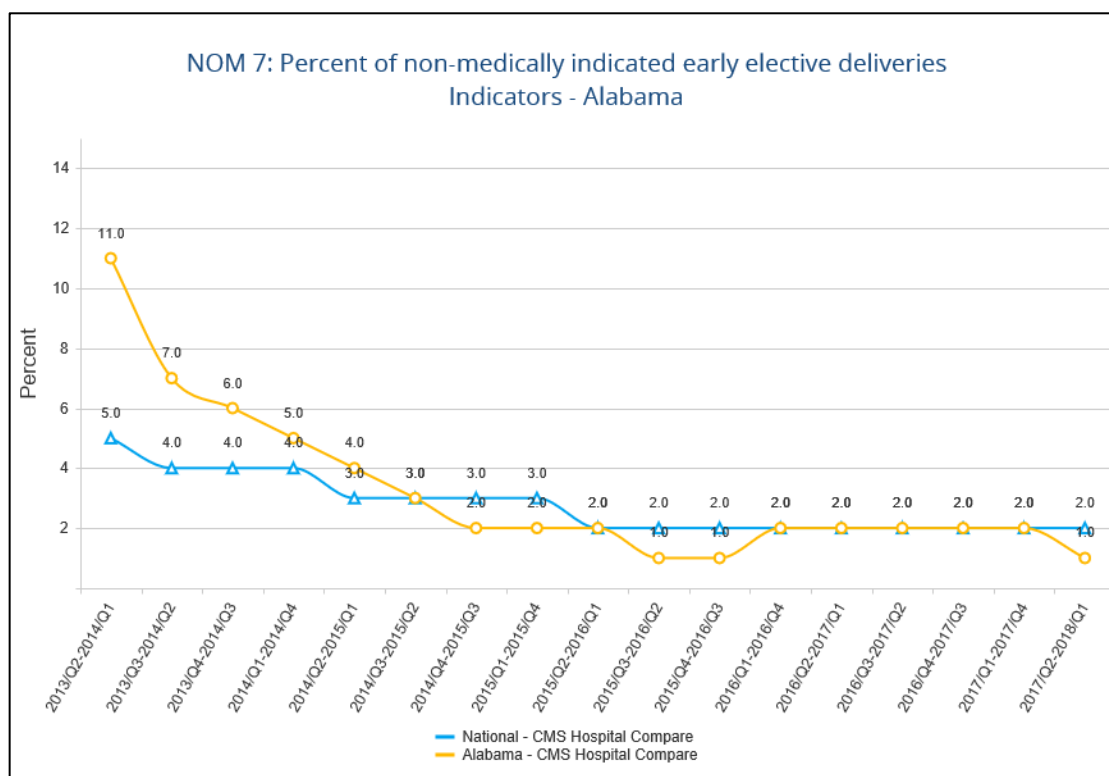
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NPM 14.1 (Percent of women who smoke during pregnancy) between 2009 and 2017. Alabama only reported data from 2014 to 2017. Both the Alabama and national data demonstrate a slightly declining trend. Alabama reported data slightly higher than the national data.



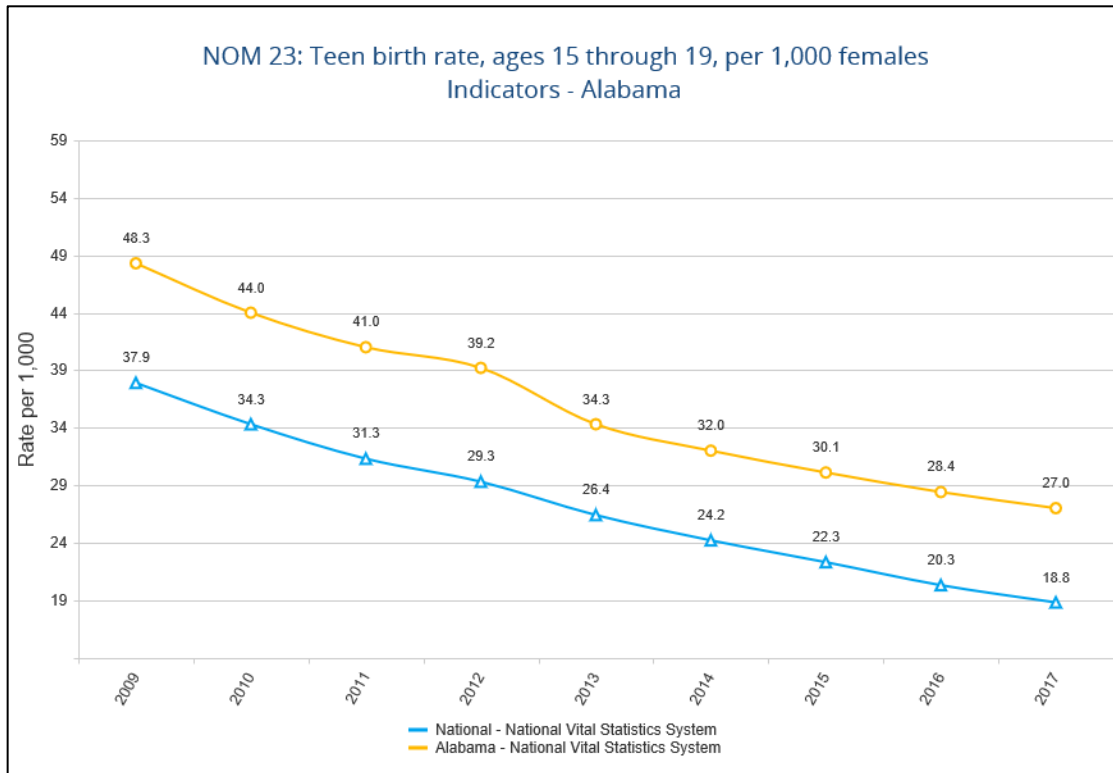
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 1 (Percent of pregnant women who receive prenatal care beginning in the first trimester) between 2009 and 2017. Alabama's percent is lower than the U.S., although the state only reported data from 2014 to 2017. Alabama's percent has declined slightly while the national average has increased steadily over time.



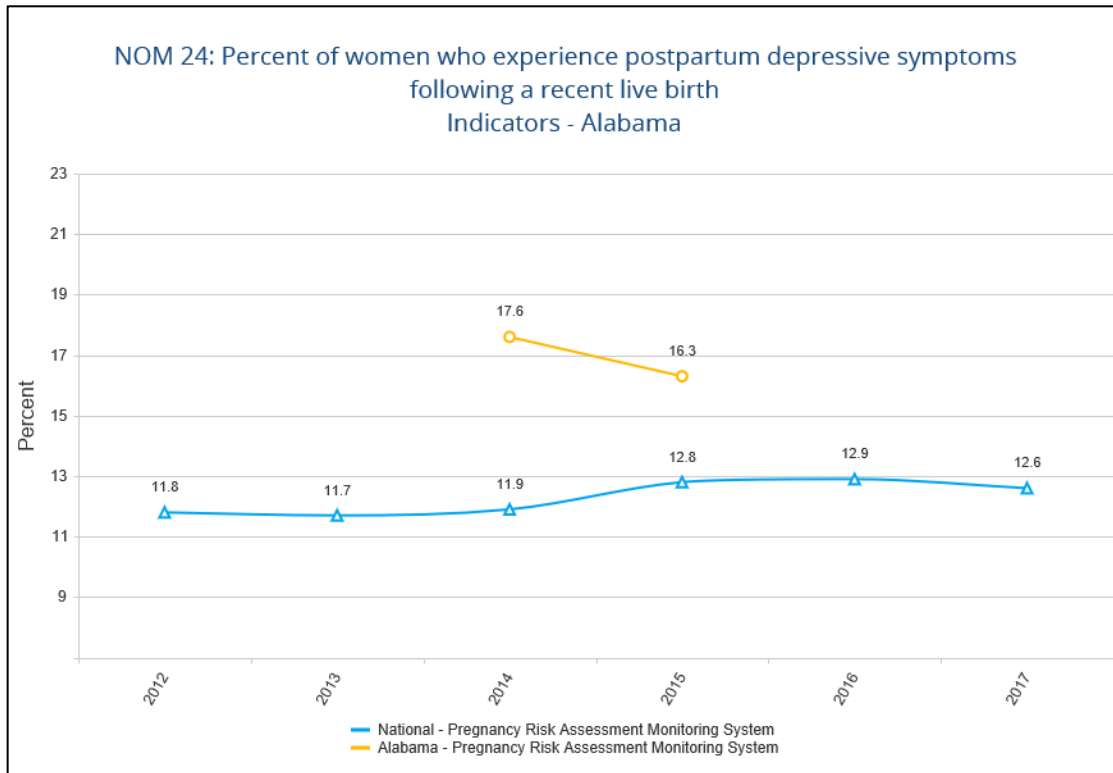
This chart presents the disparities in the percent of pregnant women who receive prenatal care beginning in the first trimester according to the most recent National Vital Statistics System data (2017). The highest percentage of pregnant women who received early prenatal care was among those with private insurance (84.0%). The lowest percentage of pregnant women who received early prenatal care was among those who were uninsured (47.8%).



The above data, from CMS Hospital Compare, display Alabama and the U.S. performance on NOM 7 (Percent of non-medically indicated early elective deliveries) between 2013 (Q3) and 2018 (Q1). Since the spring of 2013, Alabama's percent has decreased significantly. During some reporting periods, Alabama reported lower percentages than the U.S. From the beginning of 2016 through the end of 2017, the Alabama and national percentages remained steady at 2.0%. The Alabama percent fell below the national average in early 2018.



The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 23 (Teen birth rate, ages 15 through 19, per 1,000 females) between 2009 and 2017. Alabama's rates have been consistently higher than the national average; however, both Alabama and the U.S. have seen large decreases in the rates since 2009.



The above data, from the Pregnancy Risk Assessment Monitoring System (PRAMS), compare Alabama and the U.S. on NOM 24 (Percent of women who experience postpartum depressive symptoms following a recent live birth) between 2012 and 2017. Alabama only reported data in 2014 and 2015 (PRAMS data is reported to the Centers for Disease Control and Prevention annually, but only appears in the national dataset if the preset Response Rate Threshold for the year was met by the state). Although Alabama's reported data are limited, the state's percent in both 2014 and 2015 was higher than the national average.

II. Themes from Survey and Qualitative Findings

In an effort to gain more detailed information around community experiences, preferences, concerns, and perceptions, a series of focus groups, key informant interviews, and surveys were conducted in late 2019.

Focus group transcripts, key informant interview notes, and survey responses were analyzed to identify common themes across data collection methods and broad stakeholder populations. A more detailed description of the data analysis may be found on pages 3-5 of the executive summary.

Thorough analyses identified seven broad themes that describe the women's/maternal health environment in Alabama. These are described below, along with the method that yielded the supporting evidence for each theme. Due to the nature of the domains, there is similarity between some of the themes here and those in the perinatal/infant health domain.

Legend for Data Collection Method and Abbreviation

Data Collection Method	Abbreviation
Federally Available Data	F
Focus Groups	G
Key Informant Interviews	K
Surveys	S

1. **Health and Wellness** (*identified in the following Data Collection Methods: G, K, S*)
 - a. Stakeholders wanted to prevent chronic health conditions (especially diabetes, cancer, and obesity) but described many barriers to accessing healthy foods and safe spaces to exercise.
 - i. In many communities, fast food was more readily available and less expensive than healthier alternatives.
 - ii. Many stakeholders described a need for safe, affordable, and accessible recreation options for children and adults.
 - b. Physical activity was limited; nearly 79% of family survey respondents reported exercising 30 minutes per day for fewer than 5 days per week, and nearly 25% reported no days at all.
 - c. Adults were not meeting healthy nutrition guidelines; nearly 60% of family survey respondents reported only eating 1-2 servings of fruits or vegetables per day, and over half reported drinking 4 or fewer cups of water per day.
 - d. Key informants noted that there had been a shift in societal norms regarding the topic of obesity. This shift had caused the population to accept being

obese/overweight rather than viewing it as a health issue. Thus, service providers need to be prepared to address this shift with patients.

2. Mental Health (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Anxiety, depression, and suicidal thoughts were the main mental health challenges discussed.
- b. Mental health services were perceived as largely unavailable to those who are uninsured, underinsured, or covered by Medicaid.
- c. Stakeholders reported waiting between 1 and 6 months for mental health care appointments and available services tended to address crisis situations rather than non-urgent mental health needs and ongoing therapies.
- d. Stakeholders wanted preventive mental health services such as counseling, therapy, and support groups.
- e. Stigma surrounding mental health and fear of having children taken by the Department of Human Resources (DHR) prevented individuals from seeking care when they needed it.
 - i. Some shared experiences of expressing their mental health needs to their service provider and feeling their service provider cared only for their infant's well-being and not their own.
- f. Women wanted more continuous prenatal and postpartum mental health care and described experiencing postpartum depression as lonely and isolating.
 - i. Some believed postpartum depression was attributed to a mother's lack of confidence in her own parenting abilities.

3. Reproductive Health (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Stakeholders noted they had few choices when making decisions about their reproductive health care, especially near their home.
- b. Stakeholders described difficulties faced when they were uncomfortable with the birth control method they had and their service provider was unsupportive of exploring different options.
- c. Survey respondents were aware of the health department providing condoms and oral contraceptives but were less aware of the health department providing longer-acting and more reliable birth control methods.
- d. Having care preferences respected during pregnancy and labor and delivery was important to women.
- e. Women learned about reproductive health through group prenatal care, WIC classes, classes through private organizations, and social workers.
 - i. They wanted more education about nutrition, parenting, breastfeeding, postpartum mental health, and parenting children and youth with special health care needs (CYSHCN).
- f. Among key informants, early elective deliveries were perceived as less of a problem than they were 5 years ago.
- g. Focus group participants noted that tailored health information and education was desired for LGBTQ+ populations as well as women with disabilities.

- i. This included service provider education as well as information for themselves.
- h. Stakeholders noted that they or people they knew had experienced discrimination based on race, insurance status, weight, and age when accessing reproductive health care.
 - i. Some women reported that they were unable to receive referrals for tubal ligations when they wanted them due to service providers' beliefs about age, for example. However, other women reported being pressured by service providers to get tubal ligations as a result of their insurance coverage or socioeconomic status.

4. Smoking, Substance, and Alcohol Use (*identified in the following Data Collection*)

Methods: F, G, K, S)

- a. For many people, drugs and alcohol were used for stress relief and as a substitute for mental health care, which was perceived as inaccessible, unaffordable, and/or stigmatized in many communities.
- b. Stakeholders described challenges faced by low-resource individuals in accessing effective drug rehabilitation treatment.
 - i. While detox was available to many, long-term rehabilitation was not.
- c. Key informants noted an increase in neonatal abstinence syndrome (NAS) as a result of the opioid crisis
 - i. They also stated that many health care professionals were not well equipped to handle the surge of this issue due to limited education and training.
 - ii. It was also noted that it was imperative to reduce the stigma for mothers overcoming substance abuse and addiction and provide state level support for them.

5. Health Care Access, Cost, and Insurance (*identified in the following Data Collection*)

Methods: F, G, K, S)

- a. General well-woman care was not readily accessible to many stakeholders. Specialty care was even more challenging to access due to location, availability, and cost.
- b. Stakeholders described the health care system as “fragmented” and was not patient- or family-centered.
 - i. Navigating the health care system was a barrier to accessing care.
 - ii. The referral process increased the amount of time to receive appropriate treatment.
- c. Issues such as socioeconomic status, education, neighborhood crime and safety, literacy, and housing were all mentioned as barriers to health maintenance and accessing health care.
- d. Health department clinics were noted to be accessible to those who were unable to pay for other care.

- e. Service provider stakeholders noted major disparities in access to services between rural and urban areas, especially for maternity care and mental health care. They were also concerned about funding and reimbursement to support practice stability and the ability to provide comprehensive services.
 - i. In rural areas, health care workforce shortages limited access to care within a reasonable distance, especially for specialty care.
 - ii. Traveling long distances for care was difficult for individuals with limited transportation options and contributed to the high cost of care. It was common for individuals to miss a day of work in order to attend a health care appointment.
- f. The cost of insurance and care was high and could exceed what an individual or family was able to pay.
 - i. Many families earned too much to qualify for Medicaid but too little to afford private insurance.
- g. 23% of survey respondents reported that they or someone in their house did not have health insurance.
 - i. The most common reason stated for not having health insurance was that it was too expensive.
- h. Participants felt they received lower quality care when service providers were aware that they were covered by Medicaid.
- i. Several participants expressed a preference for care from a physician rather than a nurse practitioner.
 - i. They associated nurse practitioners with inferior care.
- j. Certain populations expressed unique experiences, concerns, and needs.
 - i. LGBTQ+: Stakeholders felt LGBTQ+-centered care was very difficult to find. LGBTQ+ stakeholders felt that they were refused care, receive poor quality care, were misgendered by office staff, and had the added burden of educating their service providers about specific health considerations.
 - ii. Spanish-Speaking: It could be difficult to get needed health information because educational materials in Spanish were unavailable or poorly translated. Long wait times for appointments were common because hospital staff often had to find an interpreter.
 - iii. Women with Disabilities: Women with disabilities expressed concerns about lack of accessibility and accommodations during health appointments (physical accessibility, forms and educational materials accessible for individuals who are blind or have low vision, sign language interpreters), especially for individuals without a “visible” disability. Women with disabilities wanted education tailored toward parenting with a disability (breastfeeding, carrying an infant). Some service providers did not treat women with disabilities with respect and may not have realized that having a disability does not prevent an individual from parenting capably. Survey respondents with disabilities reported lower percentages of satisfaction with health care services and service providers.

6. Oral Health Care Access, Cost, and Insurance (*identified in the following Data Collection Methods: G, K, S*)

- a. Many stakeholders did not have oral health care covered by their insurance and said that it was expensive to pay out-of-pocket.
- b. For individuals with limited resources, extractions were typically performed rather than addressing the cause of the problem.
- c. Access to oral health care was identified as a major concern for individuals in treatment for substance use.
- d. 35% of survey respondents reported that they or someone in their house did not have dental insurance.
 - i. The most common reason stated for not having dental insurance was that it was too expensive.

7. Maternal Mortality (*identified in the following Data Collection Method: K*)

- a. Service provider stakeholders were concerned about maternal mortality and noted ongoing efforts in Alabama to address this issue.
- b. There were no FAD specific to Alabama related to maternal mortality.

III. Statements of needs: Women/Maternal Domain

In considering the quantitative FAD and qualitative data presented above, 10 statements describing areas of need in the women/maternal domain were developed and presented to community stakeholders and agency leadership for discussion and prioritization. A more detailed description of the prioritization process may be found on pages 19-22 of the executive summary.

The statements, as well as their prioritized rank after the process was completed, are listed in the table below.

RANK	Potential Priority Need/Issue
1	High levels of maternal mortality
2	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
3	Inadequate or lack of comprehensive, affordable health and dental insurance
4	Lack of or inadequate access to comprehensive mental health services (prevention, crisis care, postpartum)
5	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services
6	Lack of or inadequate access to comprehensive, family-centered, and culturally competent reproductive and well-woman health care and education, including for LGBTQ populations and women with disabilities
7	Lack of or inadequate access to supports for health and wellness, including education, affordable and safe options for physical activity, and healthy foods
8	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, disability status, insurance status/type, primary language, sexual orientation, and gender identity
9	Insufficient or inadequate translated educational materials and timely interpreter services for individuals whose primary language is not English

These rankings, alongside the rankings of identified areas of needs in other domains, were then considered holistically in order to reach the final ten needs across all Title V populations. These are listed on page 26 of the executive summary.

ADPH 2020 Title V Maternal and Child Health Services Block Grant Comprehensive Needs Assessment Domain Report: Perinatal/Infant

I. Setting a Baseline for Perinatal/Infant Health in Alabama: A Summary of Federally Available Data

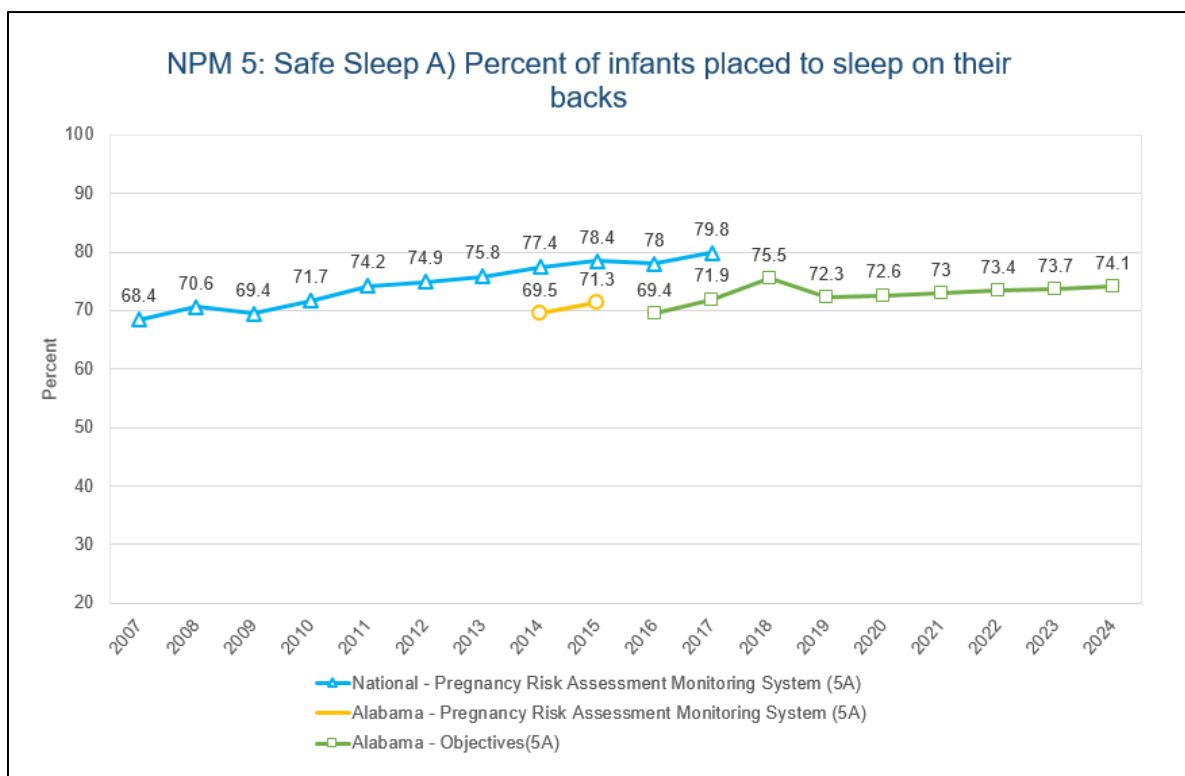
Each state is provided with a set of indicators that cover all Title V domains. These indicators are tied to the National Performance Measures and National Outcome Measures on which states have chosen to focus. The table below summarizes all the indicators that are associated with perinatal/infant health for Alabama. Note: Some data were unavailable for examination across time due to changes in collection strategies at the federal level.

Perinatal/Infant Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Risk-appropriate perinatal care – very low birth weight babies born in hospitals with Level III+ NICU	84.1%	NA	Trending better
Breastfeeding – ever	68.1%	Worse	About the same
Breastfeeding – exclusively through 6 months	20.6%	Worse	Trending better
Safe sleep – infant placed on back	71.3%	Worse	About the same
SUID mortality	216.4 per 100,000	Worse	Trending worse
Infant mortality	9.0 per 1,000	Worse	Mixed
Preterm birth	12.0%	Worse	About the same
Low birth weight	10.3%	Worse	About the same
Early elective delivery	1.0%	About the same	Trending better

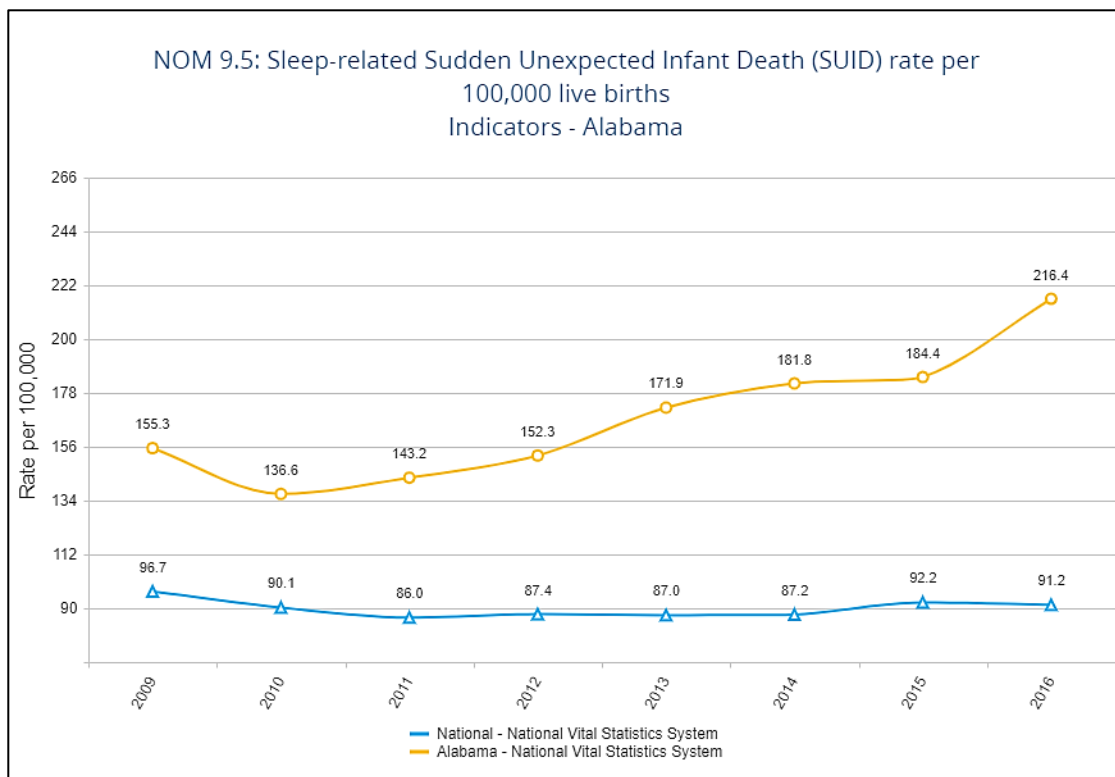
*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arrears. See page 3 for information on FAD and to access current information.

In keeping with the guiding principle of promoting health equity and reducing disparities, several areas of disparity were noted across all domains in both the Federally Available Data (FAD) and qualitative findings. For this domain, indicator data show differences in outcomes based on race, ethnicity, socioeconomic status, parental education, and insurance status and type. Furthermore, these inequities are driven by many factors, including social determinants of health like education, poverty, structural racism, and housing safety and quality. Notable disparities in sentinel indicators are also presented below in conjunction with the indicators' Alabama-U.S. comparisons.

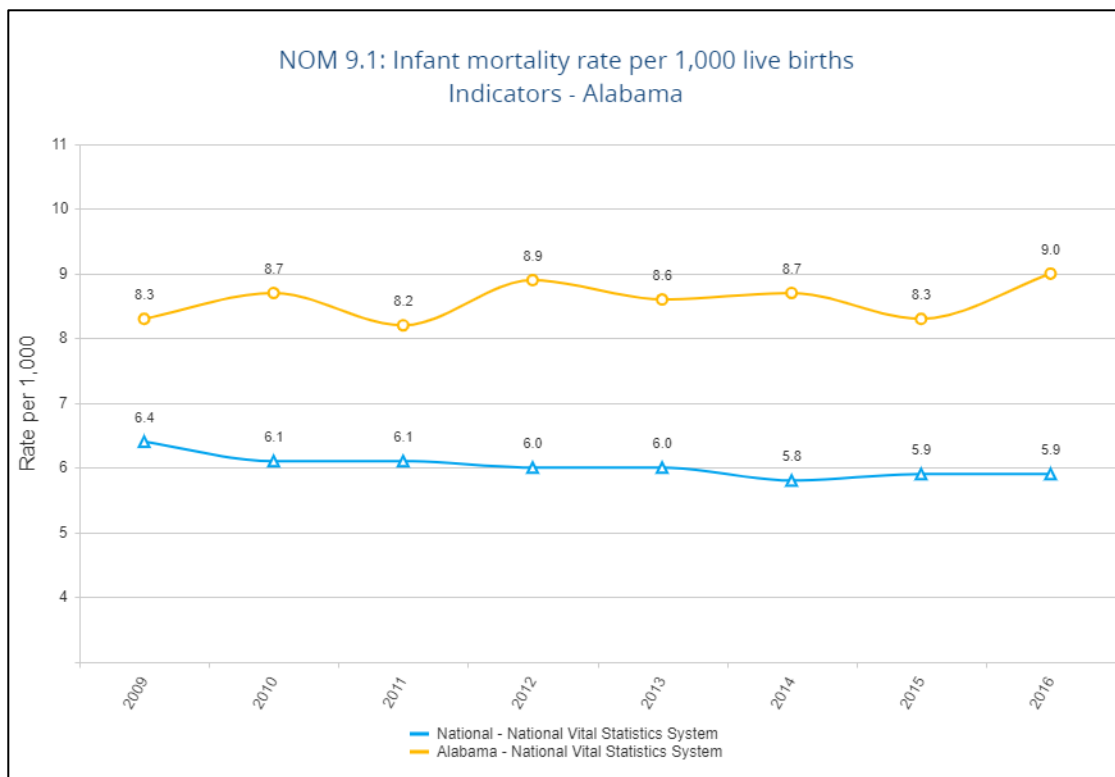
The following charts present the above data in more detailed form and, where available, across time to show comparisons to national indicators and trends.



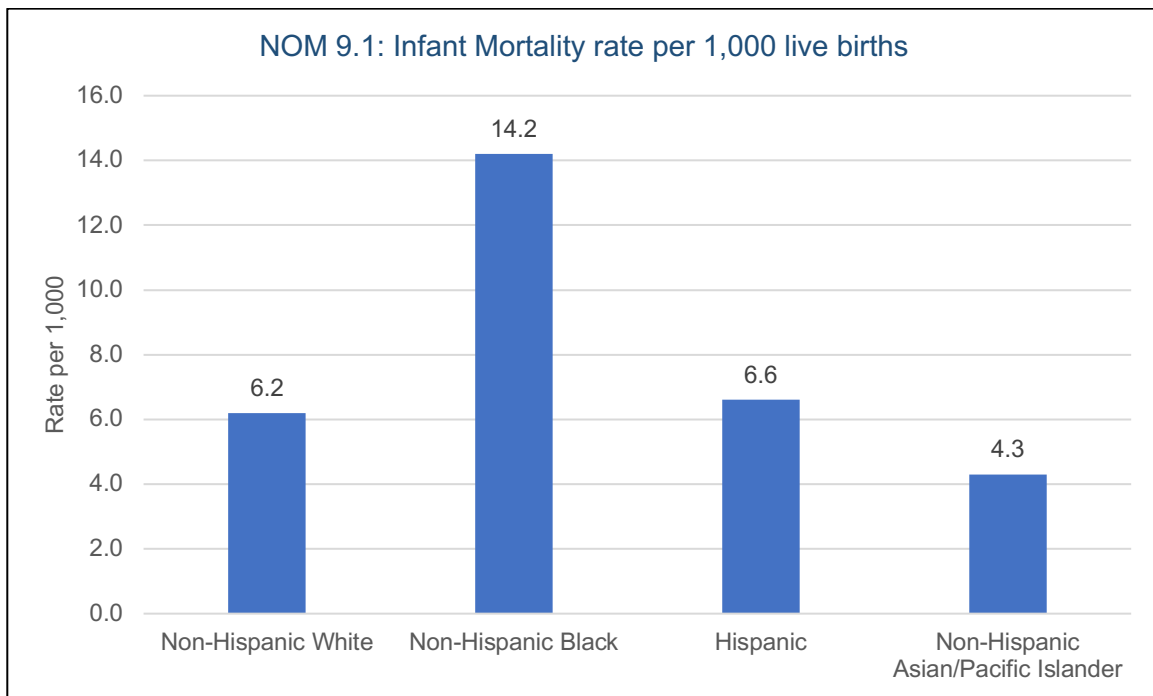
The above data, from the Pregnancy Risk Assessment Monitoring System (PRAMS), compare Alabama and the U.S. on NOM 5(A) (Percent of infants placed to sleep on their backs) between 2007 and 2017. Alabama only reported data in 2014 and 2015 but, between these two years, the percent increased. (PRAMS data is reported to the Centers for Disease Control and Prevention annually, but only appears in the national dataset if the preset Response Rate Threshold for the year was met by the state). Nationally, the percent has increased steadily between 2007 and 2017 and is higher than Alabama's reported data. The green data points indicate Alabama's objectives for the coming years.



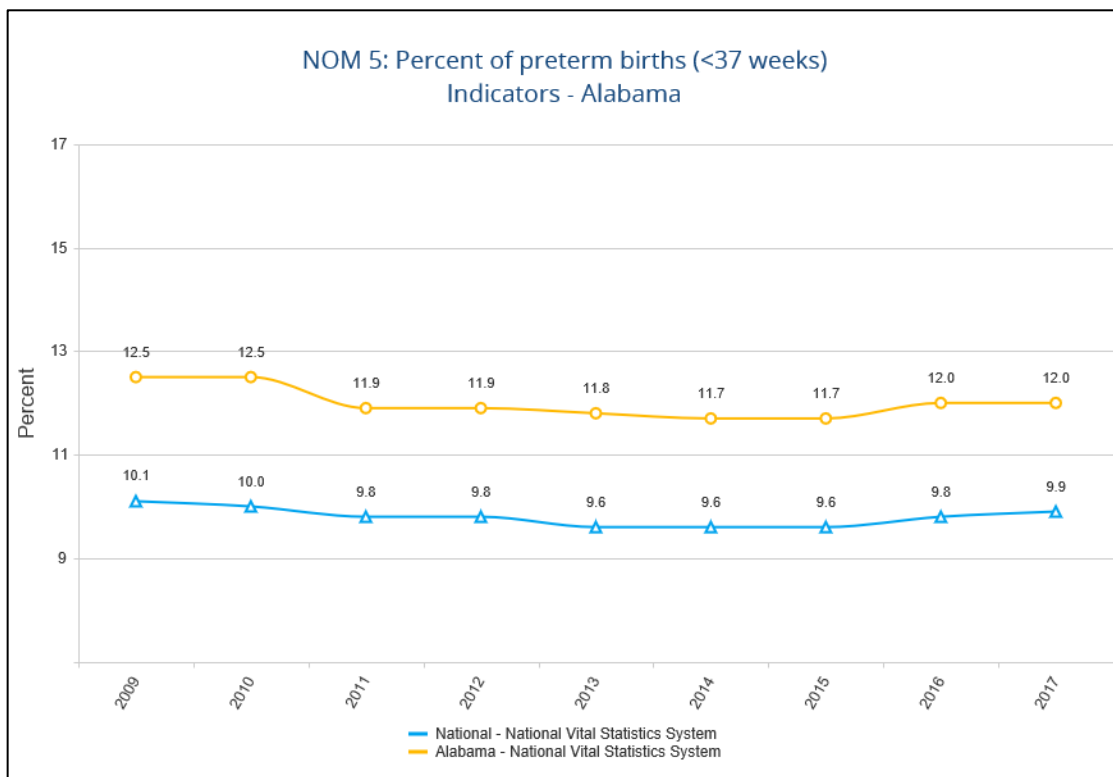
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 9.5 (Sleep-related Sudden Unexpected Infant Death [SUID] rate per 100,000 live births) between 2009 and 2016. After an initial decrease from 2009 to 2010, Alabama's SUID rate has steadily increased over time. This increasing trend strays from the national trend, which has remained stable and significantly lower than the Alabama SUID rate.



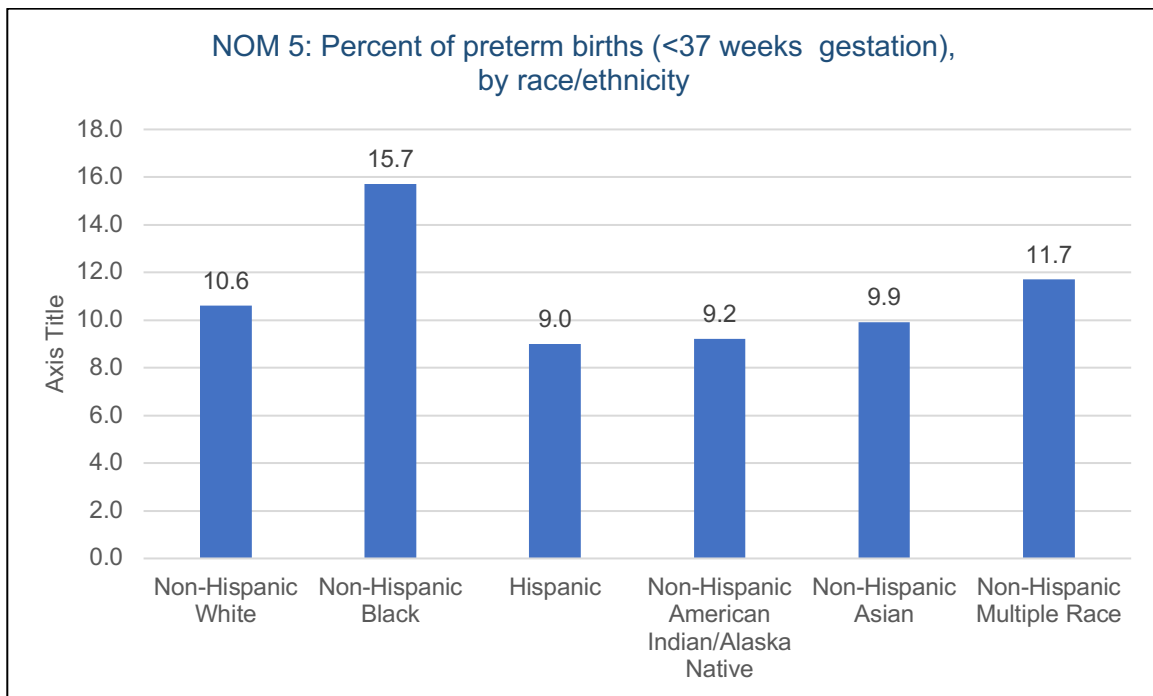
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 9.1 (Infant mortality rate per 1,000 live births) between 2009 and 2016. Alabama's rate has remained between 8.3 and 9.0 infant deaths per 1,000 live births with slight fluctuations from year to year. The state's rate is consistently higher than the national rate, which has remained relatively stable over the years.



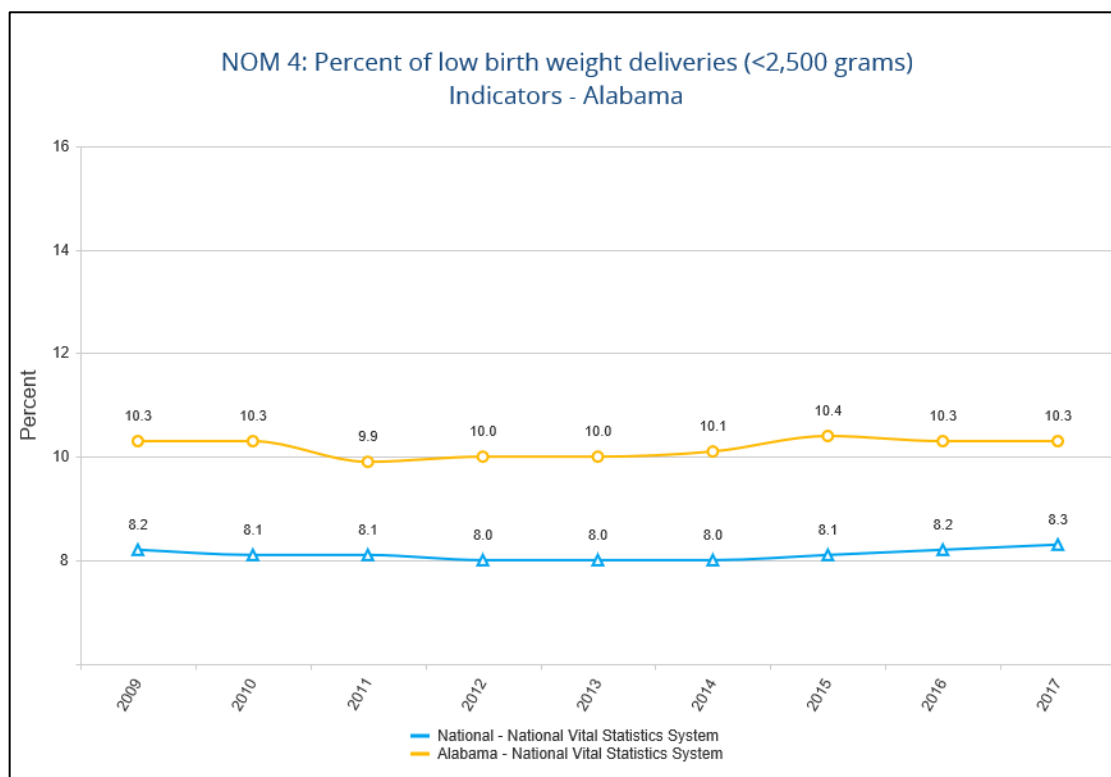
This chart presents the disparities in the infant mortality rate per 1,000 live births by race and ethnicity according to the most recent National Vital Statistics System data (2017). The highest infant mortality rate was among Non-Hispanic Black infants. The lowest rate was among Non-Hispanic Asian/Pacific Islander infants.



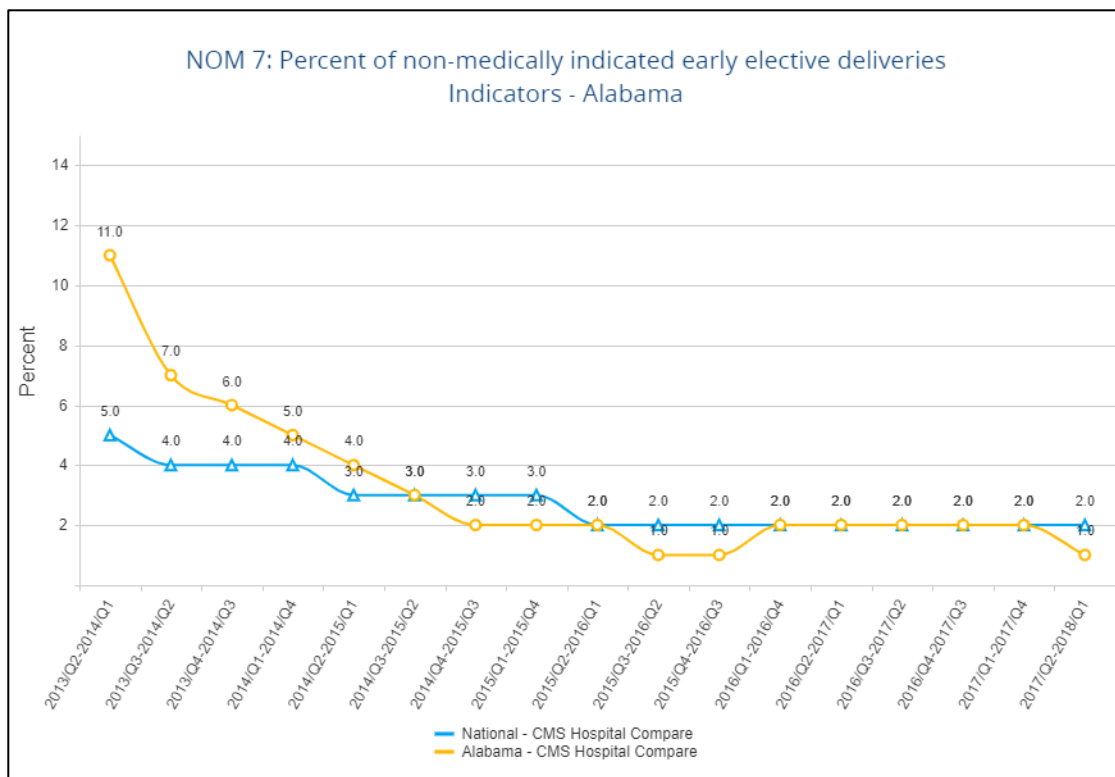
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 5 (Percent of preterm births [<37 weeks]) between 2009 and 2017. Alabama's percent is consistently higher than the nation's. Both the state and the U.S. reported slight increases in their percentages in 2016 and 2017 after several years of stability.



This chart presents the disparities in the percent of preterm births by race and ethnicity according to the most recent National Vital Statistics System data (2017). The highest percentage of preterm births was among Non-Hispanic Black women. The lowest percentage was among Hispanic women with similar percentages among Non-Hispanic American Indian/Alaska Native and Non-Hispanic Asian women.



The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 4 (Percent of low birth weight deliveries [<2,500 grams]) between 2009 and 2017. Alabama consistently reports a higher percent than the nation. Both the state and U.S. report stable trends with very slight variation from year to year.



The above data, from CMS Hospital Compare, display Alabama and the U.S. performance on NOM 7 (Percent of non-medically indicated early elective deliveries) between 2013 (Q3) and 2018 (Q1). Since the spring of 2013, Alabama's percent has decreased significantly. During some reporting periods, Alabama reported lower percentages than the U.S. From the beginning of 2016 through the end of 2017, the Alabama and U.S. percentages remained steady at 2.0%. The Alabama percentage fell below the national average in early 2018.

II. Themes from Survey and Qualitative Findings:

In an effort to gain more detailed information around community experiences, preferences, concerns, and perceptions, a series of focus groups, key informant interviews, and surveys were conducted in late 2019.

Focus group transcripts, key informant interview notes, and survey responses were analyzed to identify common themes across data collection methods and broad stakeholder populations. A more detailed description of the data analysis may be found on pages 3-5 of the executive summary.

Thorough analyses identified eight broad themes that describe the perinatal/infant health environment in Alabama. These are described below, along with the method that yielded the supporting evidence for each theme. Due to the nature of the domains, there is similarity between some of the themes here and those in the maternal/women's domain.

Legend for Data Collection Method and Abbreviation

Data Collection Method	Abbreviation
Federally Available Data	F
Focus Groups	G
Key Informant Interviews	K
Surveys	S

- 1. Pregnant and Parenting Teens and Young Families/New Parents (*identified in the following Data Collection Methods: G, K, S*)**
 - Teen, young, and new/first-time parents lacked access to parenting education, guidance, and mentorship related to pregnancy, delivery, and raising their children; some felt isolated or unprepared.
 - New parents reported difficulties accessing a safe car seat and crib.
 - There was also the perception that births to teens drove the infant mortality rate due to a lack of mentorship and guidance.
 - Individuals covered by Medicaid during their pregnancy reported receiving more parenting education than during subsequent births when they were covered by private insurance.
- 2. Safe Sleep Education (*identified in the following Data Collection Methods: F, G, K, S*)**
 - The majority of community stakeholders were aware of safe sleep guidelines.
 - Many noted that multiple service providers had discussed safe sleep with them or provided classes (WIC, Department of Human Resources [DHR], home visiting, and their health care provider).
 - A few noted that, in the hospital following delivery, nurses should stress safe sleep more.

- b. Some parents and caregivers struggled to access important supplies, such as cribs that align with the safe sleep guidelines.
- c. Key informants noted a need to recognize and appropriately address cultural issues around co-sleeping.
- d. Top reasons given by family survey respondents for difficulty in following safe sleep guidelines were:
 - i. Having baby in bed makes night-time feedings easier (66%)
 - ii. A “family bed” or having baby sleep in bed with family is preferable (52%)
 - iii. Baby will be safer in bed with family (50%)
 - iv. Other people in family haven’t done all of these things [“Followed safe sleep guidelines”] (47%)

3. Breastfeeding (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Many women stakeholders said they preferred to breastfeed but felt it was unsustainable without support so had to switch to formula.
 - i. There was a perceived lack of support from service providers and older family members.
 - ii. There was also encouragement to use formula from these groups.
- b. Lactation support was available for most women immediately after delivery (especially in hospitals), but long-term support was unavailable in the community, especially for women who did not qualify for WIC or other support services.
- c. Some participants shared that the WIC benefit they received was not enough to feed their infant, especially if they were also breastfeeding.
- d. There was a desire for tailored information for how to breastfeed if you were a woman with a disability as well as how to breastfeed a child with special health care needs.

4. Infant Mortality (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Despite recent statewide focus, 63% of family survey respondents didn’t know or weren’t sure of the trends on how Alabama was doing related to infant mortality.
- b. Stakeholders felt that limited access to consistent, high quality care might have contributed to the high rate of infant mortality in Alabama.
 - i. This included health education as well as primary, prenatal, postnatal, and mental health care.
- c. Service providers and key informants felt that infant mortality was related to many issues, including preterm birth, low birthweight, co-sleeping, poverty, systemic racism, smoking, substance abuse, lack of access to family planning services, and poor overall health of the mother.
- d. Service providers were also concerned about the loss of delivery hospitals in rural areas.
- e. Stakeholders also proposed solutions including increased focus on parenting education, expansion of home visiting and the Baby Box program, and support for pregnant women with substance use disorder.

5. Mental Health (*identified in the following Data Collection Methods: G, K, S*)

- a. Many stakeholders described issues with postpartum depression. Women wanted more, continuous prenatal and postpartum mental health care and described experiencing postpartum depression as lonely and isolating.

- b. Community stakeholders noted stigma related to seeking postpartum mental health care as well as a fear of having children taken by DHR were they to seek care for mental health concerns.
- c. Some shared experiences of expressing their mental health needs to their provider and feeling their provider cared only for their infant's well-being and not their own.
- d. Stakeholders wanted preventive mental health services, such as counseling, therapy, and support groups in addition to crisis services.
- e. Mental health services were perceived as largely unavailable to those who were uninsured, underinsured, or covered by Medicaid.
- f. Participants shared that pregnancy, particularly if unplanned, could lead to increased stress and mental health challenges.

6. Reproductive and Prenatal/Perinatal Care (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Stakeholders felt they had few choices when making decisions about their reproductive health, especially near their home.
 - i. Service providers were particularly concerned about the closing of rural hospitals.
- b. Women wanted high quality and frequent prenatal care, lengthened postpartum care in the hospital, nutrition education through pregnancy, and postpartum mental health care access.
- c. Having care preferences respected was important to women throughout pregnancy and during labor and delivery.
 - i. Some participants preferred midwifery to obstetric care.
- d. Stakeholders wanted to be sure that infants had equal access to newborn screening, regardless of obstetric care and delivery choice.
- e. Key informants noted a need to explore policy and legislative options to expand women's access to care.
- f. Service providers noted that early elective deliveries were not as large of an issue as they were 5 years ago.

7. Smoking, Substance, and Alcohol Use (*identified in the following Data Collection Methods: G, K, S*)

- a. For many people, drugs and alcohol were used for stress relief and as a substitute for mental health care. This could lead to neonatal abstinence syndrome (NAS) and other poor outcomes.
- b. Stakeholders described challenges faced by low-resource individuals in accessing effective drug treatment.
 - i. While detox was available to many, long-term rehabilitation was not.
- c. Those who wanted to seek help for substance use and addiction were unable due to the cost and limited availability of services.
- d. There was stigma attached to seeking treatment for substance abuse and addiction and fear of jail time and/or losing custody of children.
- e. Key informants identified a need for alternatives to current methods of managing pregnant women who were also dealing with substance use disorder.

- f. Key informants noted the increase in NAS and were concerned that health care professionals were not well equipped to handle the surge due to limited education and training.

8. Health/Dental Care Access, Cost, and Insurance (*identified in the following Data Collection*

Methods: G, K, S)

- a. Stakeholders described the health care system as “fragmented” and not patient- or family-centered.
- b. Provider stakeholders noted major disparities in access to services between rural and urban areas. Health care workforce shortages limited access to care within a reasonable distance, especially for specialty care.
- c. Service providers were concerned about required paperwork burden and low reimbursement as barriers to accepting Medicaid, practice stability, providing comprehensive care.
- d. Service providers noted many services were not available, with lack of insurance coverage and patient inability to pay for services as major barriers.

III. Statements of needs: Perinatal/Infant Health Domain

In considering the quantitative FAD and qualitative data presented above, 10 statements describing areas of need in the perinatal/infant health domain were developed and presented to community stakeholders and agency leadership for discussion and prioritization. A more detailed description of the prioritization process may be found on pages 19-22 of the executive summary.

The statements, as well as their prioritized rank after the process was completed, are listed in the table below.

RANK	Potential Priority Need/Issue
1	High levels of infant mortality (and associated factors of preterm birth and low birth weight)
2	High levels and worsening trends of sleep-related/SUID deaths
3	Inequitable access to health resources (including delivery hospitals) based on race/ethnicity, socioeconomic status, geographic location, and education
4	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services
5 (tie)	Lack of or inadequate access to comprehensive reproductive health care
5 (tie)	Lack of or inadequate comprehensive, affordable health and dental insurance
7	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, insurance status/type, and primary language
8 (tie)	Lack of or inadequate access to breastfeeding supports
8 (tie)	Lack of supports for pregnant and parenting teens and young/new parents
10	Lack of or inadequate access to comprehensive mental health services (prevention, crisis care, postpartum)

These rankings, alongside the rankings of identified areas of needs in other domains, were then considered holistically in order to reach the final 10 needs across all Title V populations. These are listed on page 26 of the executive summary.

ADPH 2020 Title V Maternal and Child Health Services Block Grant Comprehensive Needs Assessment *Domain Report: Child*

I. Setting a Baseline for Child Health in Alabama: A Summary of Federally Available Data

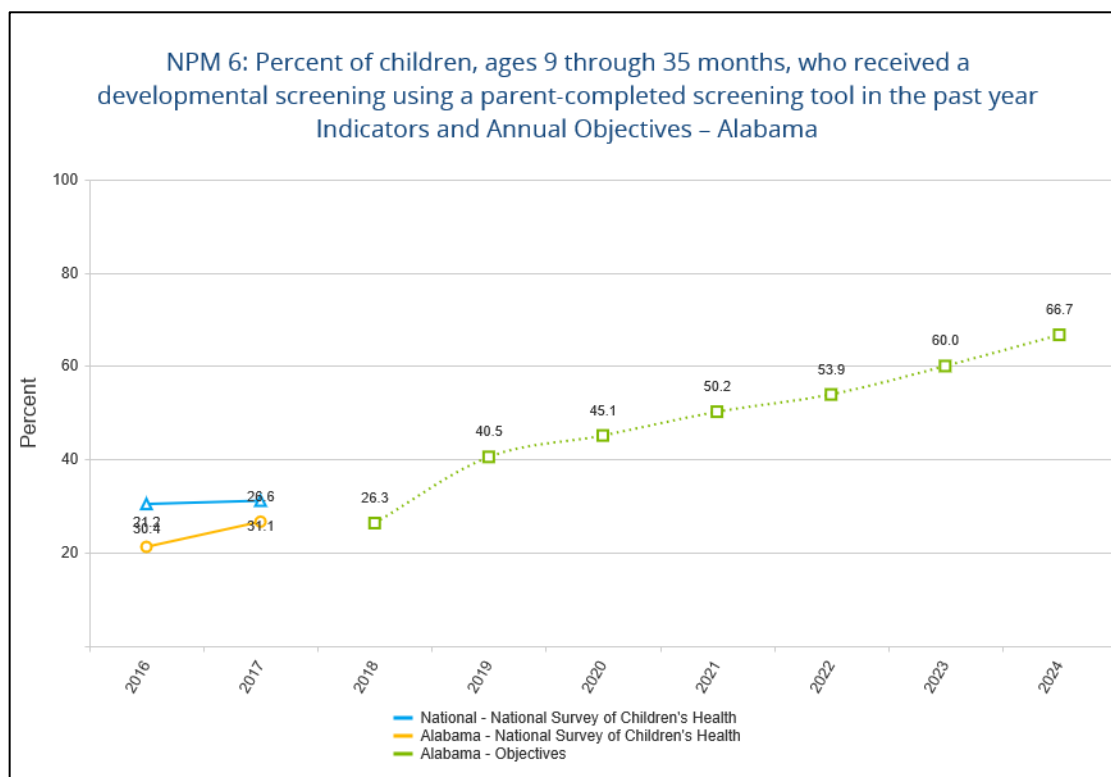
Each state is provided with a set of indicators that cover all Title V domains. These indicators are tied to the National Performance Measures and National Outcome Measures on which states have chosen to focus. The table below summarizes all of the indicators that are associated with child health for Alabama. Note: Some data were unavailable for examination across time due to changes in collection strategies at the federal level.

Child Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Developmental screening (9-35 months)	26.6%	Worse	Trending better
Physical activity (6-11 years, every day)	26.8%	About the same	About the same
Preventive dental visit – child (6-11 years)	91.5%	Better	About the same
Child mortality	24.6 per 100,000	Worse	Trending better
Obesity (2-4 years)	16.3%	Worse	Trending worse
Child vaccination (19-35 months)	71.2%	About the same	Trending better

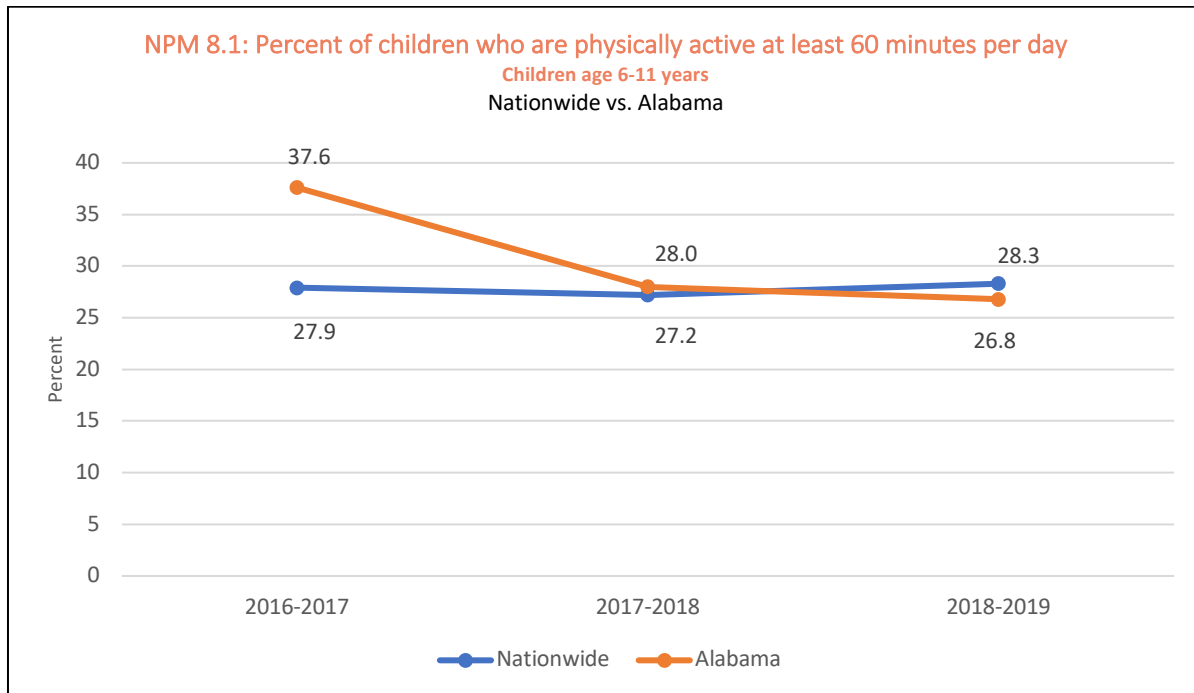
*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arears. See page 3 for information on FAD and to access current information.

In keeping with the guiding principle of promoting health equity and reducing disparities, several areas of disparity were noted across all domains in both the Federally Available Data (FAD) and qualitative findings. For this domain, indicator data show differences in outcomes based on race, ethnicity, socioeconomic status, parental education, and insurance status and type. Furthermore, these inequities are driven by many factors, including social determinants of health like education, poverty, structural racism, and housing safety and quality. Notable disparities in sentinel indicators are also presented below in conjunction with the indicators' Alabama-U.S. comparisons.

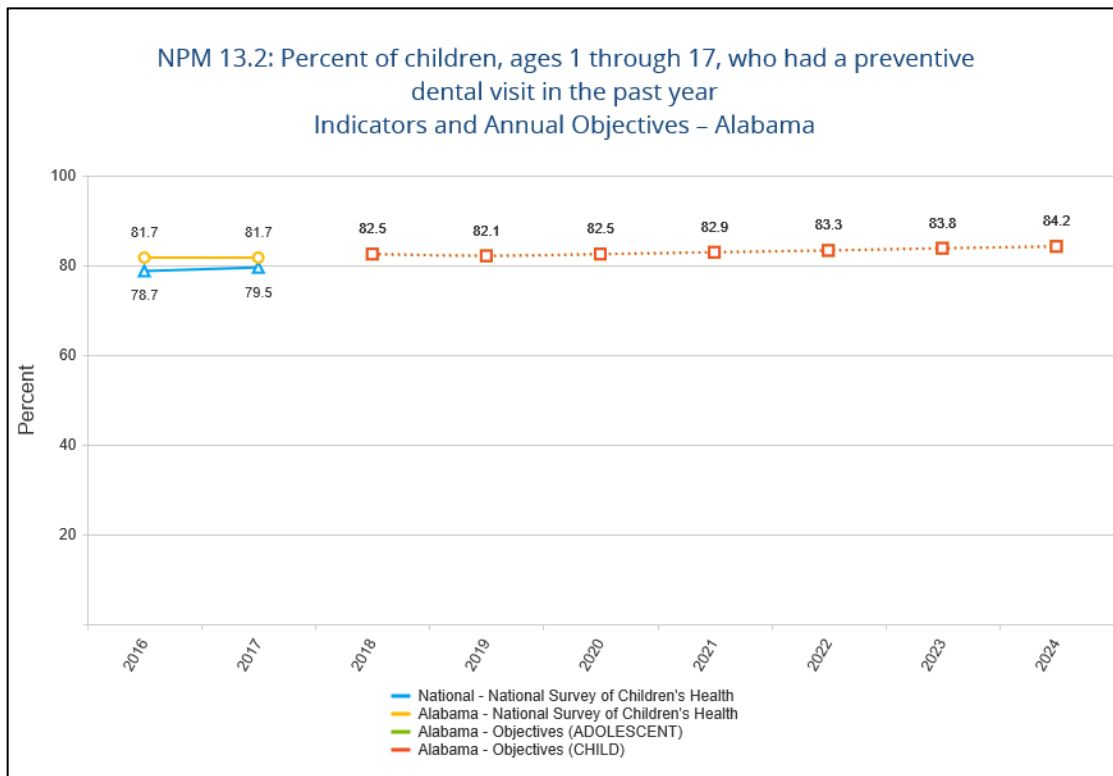
The following charts present the above data in more detailed form and, where available, across time to show comparisons to national indicators and trends.



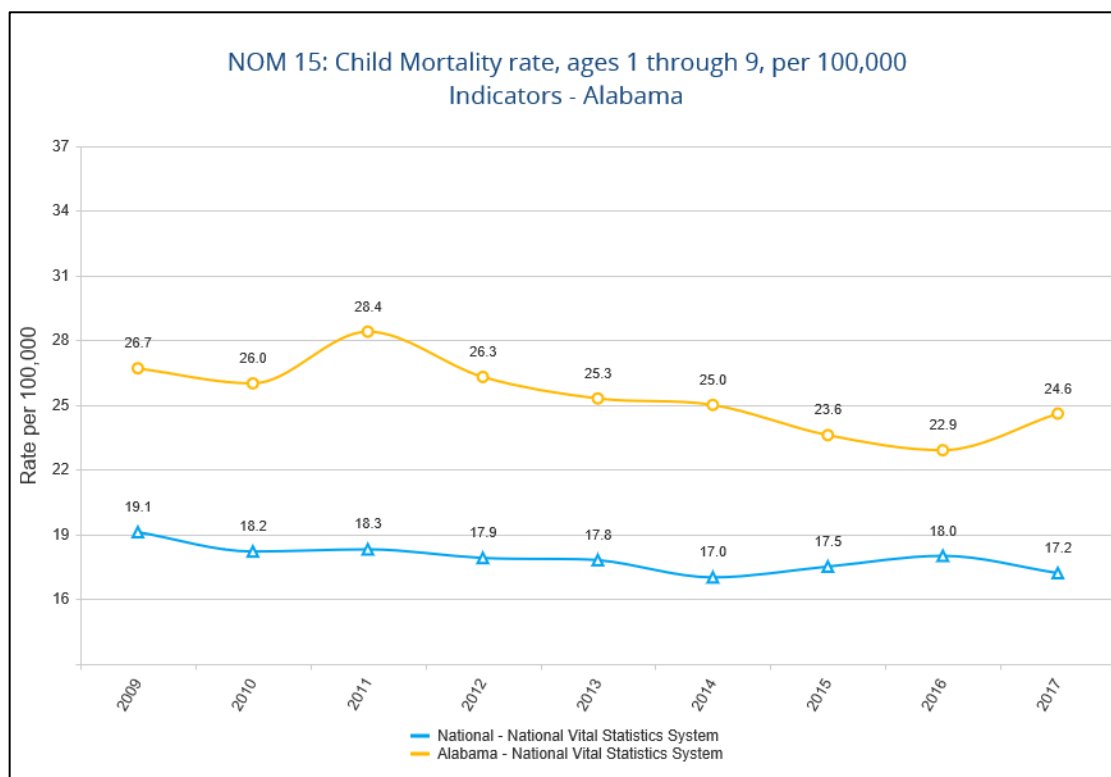
The above data compare Alabama and the U.S. on NPM 6 (Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year) between 2016 and 2017. For both years, Alabama reported lower percentages than the national average; however, there was an increase from 2016 to 2017. The green line indicates the state's objectives for the coming years.



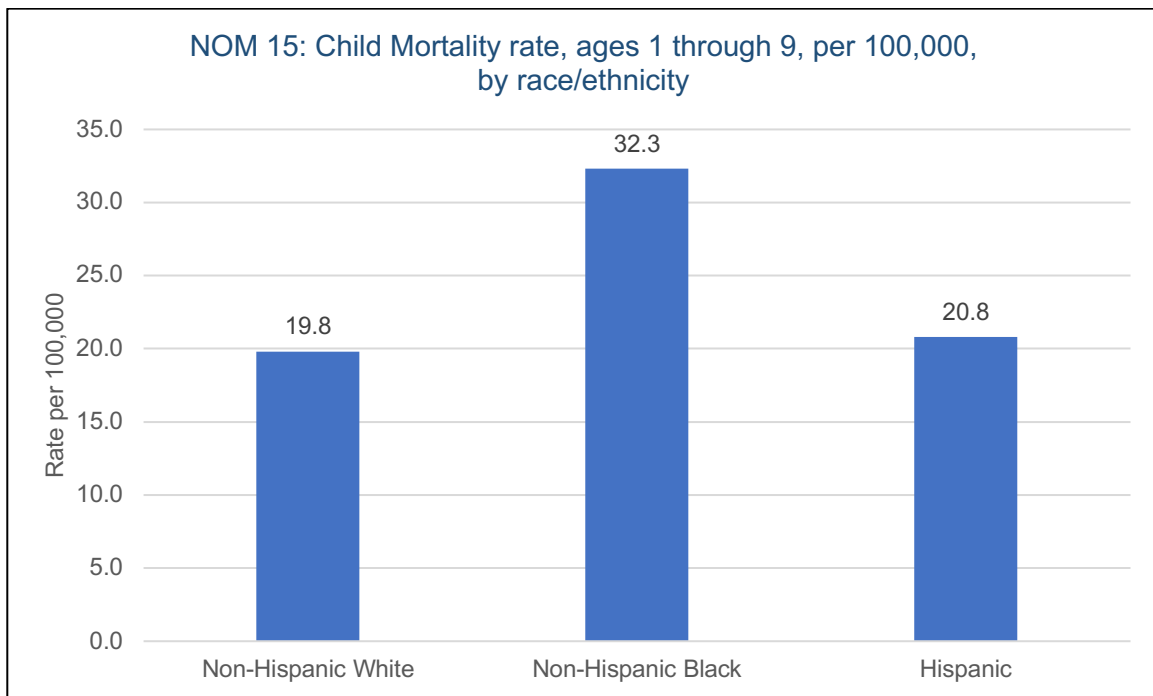
The above data, from the National Survey of Children's Health, compares Alabama and the U.S. on NPM 8.1 (Percent of children who are physically active at least 60 minutes per day, children aged 6-11 years). Comparisons must be made using pooled data from two survey years due to small sample sizes. Across the three survey iterations, nationwide percentages have been fairly stable. Other than the initial estimate in 2016-2017 (which may be an outlier), Alabama percentages have been fairly stable as well. Alabama and nationwide estimates are similar for this measure.



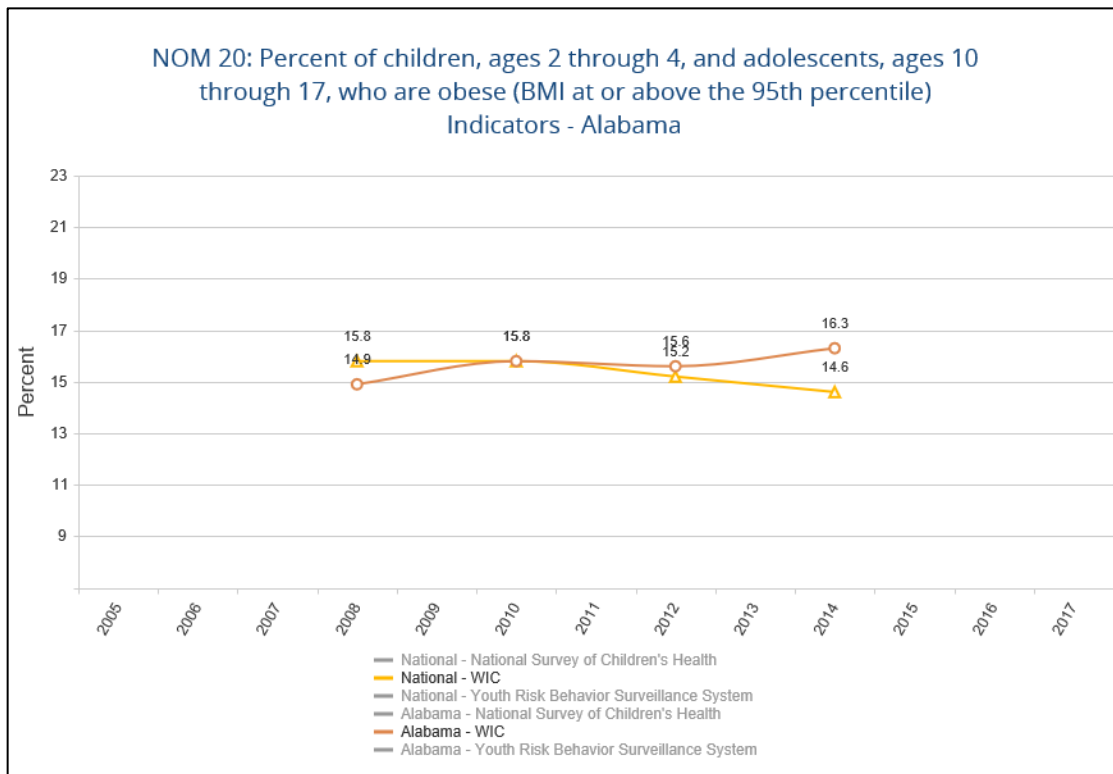
The above data, from the National Survey of Children’s Health, compare Alabama and the U.S. on NPM 13.2 (Percent of children, ages 1 through 17, who had a preventive dental visit in the past year). Alabama reported higher percentages than the national average in both 2016 and 2017. Both nationally and in Alabama, percentages remained stable. The orange line indicates the state’s objectives for the coming years.



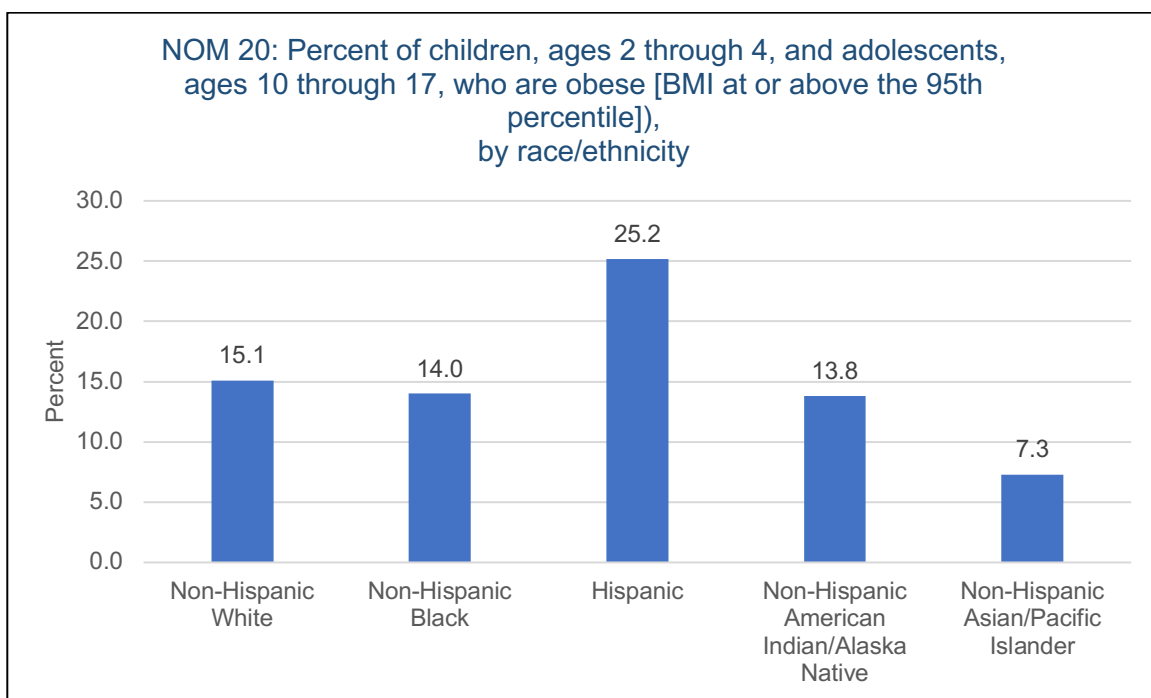
The above data, from the National Vital Statistics System, compare Alabama and the U.S. on NOM 15 (Child Mortality rate, ages 1 through 9, per 100,000). Alabama consistently reports significantly higher rates than the national rates. Except for one spike in 2011, Alabama has seen a decline in the rate from 2009 to 2016. From 2016 to 2017, Alabama reported an increase in the child mortality rate while the U.S. reported a slight decrease.



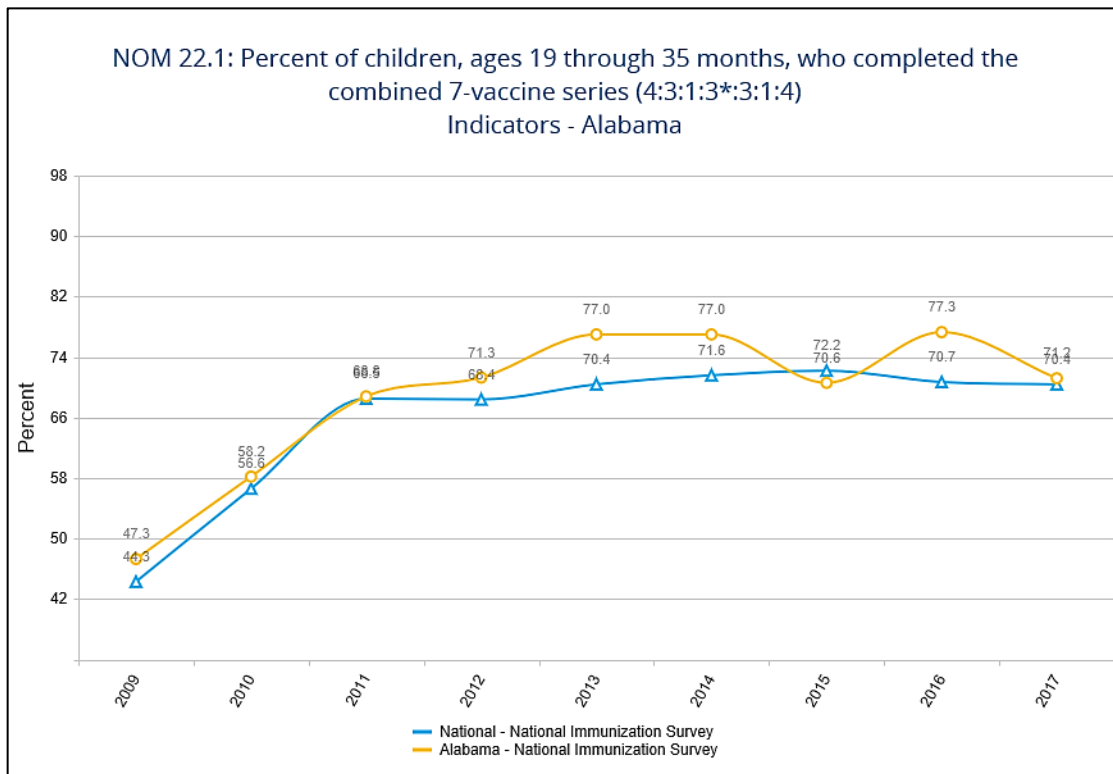
This chart presents the disparities in the child mortality rate by race and ethnicity according to the most recent National Vital Statistics System data (2015-2017). The mortality rates for Non-Hispanic White children and Hispanic children are very similar, whereas the mortality rate for Non-Hispanic Black children is significantly higher.



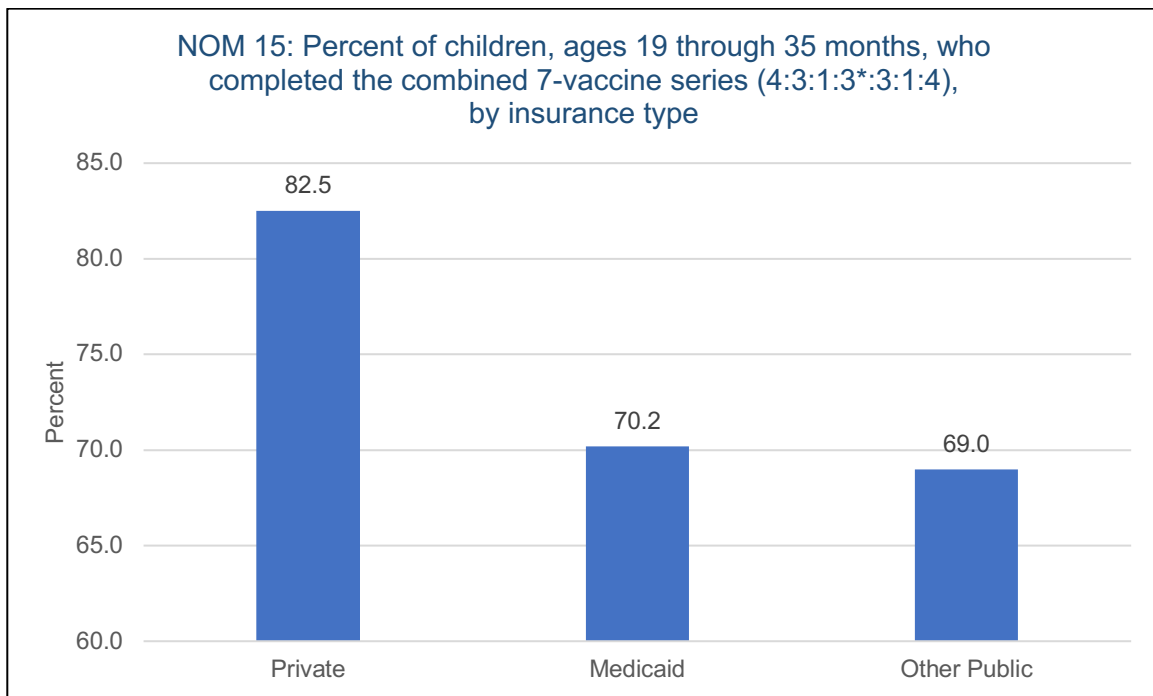
The above data, from the Women, Infant, and Children's program, compare Alabama and the U.S. on NOM 20 (Percent of children, ages 2 through 4 who are obese [BMI at or above the 95th percentile]) between 2008 and 2014. The national percentage slowly declined and the Alabama percentage increased over the 6-year period. Although Alabama first reported a percentage lower than the national percentage, in 2012 and 2014 the state surpassed the national percentage.



This chart presents the disparities in the percent of children who are obese by race and ethnicity according to the most recent available Women, Infant, and Children's program data (2014). Over 25% of Hispanic children were obese, the highest percentage of any racial or ethnic group. Non-Hispanic Asian/Pacific Islander children reported the lowest percentage of obesity. Non-Hispanic White, Non-Hispanic Black, and Non-Hispanic American Indian/Alaska Native percentages were very similar.



The above data, from the 2017 National Immunization Survey, compare Alabama and the U.S. on NOM 22.1 (Percent of children, ages 19 through 35 months, who completed the combined 7-vaccine series). Both the U.S. and Alabama have reported increased percentages since 2009; however, Alabama has reported more fluctuations in the percentage. Most years, Alabama maintained percentages above the U.S.; however, in 2015, the state's percentage dropped below the U.S.



This chart presents disparities in the percent of children who completed the combined 7-vaccine series by insurance type according to the 2017 National Immunization Survey. Children with private insurance reported a higher percentage of having completed the 7-vaccine series compared with those insured by Medicaid or another public insurance program.

II. Themes from Survey and Qualitative Findings

In an effort to gain more detailed information around community experiences, preferences, concerns, and perceptions, a series of focus groups consisting of parents of children, key informant interviews, and surveys were conducted in late 2019.

Focus group transcripts, key informant interview notes, and survey responses were analyzed to identify common themes across data collection methods and broad stakeholder populations. A more detailed description of the data analysis may be found on pages 3-5 of the executive summary.

Thorough analyses identified seven broad themes that describe the child health environment in Alabama. These are described below, along with the method or methods that yielded the supporting evidence for each theme.

Legend for Data Collection Method and Abbreviation

Data Collection Method	Abbreviation
Federally Available Data	F
Focus Groups	G
Key Informant Interviews	K
Surveys	S

1. Health and Wellness (*identified in the following Data Collection Methods: G, K, S, F*)

- a. Physical activity was limited among young children, which was perceived to be caused by overuse of technology.
- b. Safe and affordable recreational options were limited for some families.
 - i. Gyms, parks, etc. were uncommon or too expensive for some families to use or were not safe due to high crime rates in certain communities.
- c. Young children were not meeting healthy nutrition guidelines.
 - i. Nearly 80% of family survey respondents reported their child ate 4 or fewer servings of fruits or vegetables per day; 75% reported their child drank 4 or fewer cups of water per day.
- d. School lunches were a barrier to children adopting healthy diets due to the limited healthy options.
 - i. However, schools could provide unique opportunities for nutrition education.
- e. There was a lack of knowledge about portion sizes for children, leading to overeating and childhood obesity.
 - i. WIC may be a vehicle for supporting education around this issue.
 - ii. University extension programs were perceived as useful and supportive for nutrition education in communities.

2. Safe, Affordable Childcare; Preschool Programs; Home Visiting; and Early Intervention Services (*identified in the following Data Collection Methods: G, K, S*)

- a. Parents wanted safe, affordable, quality childcare options, especially for young children.
- b. Parents wanted expanded preschool, home visiting, and early intervention service availability.
- c. Transportation, cost, and hours of operation were barriers to accessing these services.
- d. Parents wanted more training for teachers and childcare workers and better accessibility to these services for children with disabilities and special needs.

3. Pregnant and Parenting Teens and Young Families/New Parents (*identified in the following Data Collection Methods: G, K, S*)

- a. Teen, young, and new/first-time parents lacked access to or were unaware of where to find parenting education, guidance, and mentorship related to raising their children, feeling isolated or unprepared.
- b. There were concerns related to supporting overall parenting skills, appropriate discipline, breastfeeding, and recognition of quality health services.
- c. Stakeholders wanted community classes or similar supports to address this need.
- d. Targeted information, materials, or classes for non-English speakers and parents with disabilities were also highly sought after by those populations.

4. Child Mental Health (*identified in the following Data Collection Methods: G, K, S*)

- a. Stakeholders were concerned about access to mental health service providers who have expertise in working with children.
- b. Services were difficult to obtain due to cost, insurance coverage, and workforce shortage.
- c. Stakeholders noted that bullying in schools had increased, especially with the rise in bullying through social media platforms, and suicidal thoughts had become more prominent among children.
- d. Key informants, in particular, noted that mental health services were needed across the lifespan, and intervention for identified needs should begin at an early age. This included early identification and intervention of developmental and other behavioral diagnoses.

5. Smoking, Substance, and Alcohol Use (*identified in the following Data Collection Methods: G, K, S*)

- a. Drugs and alcohol were widely available in many communities, including to school age children. Stakeholders noted that children began smoking and using substances at younger ages.
- b. Many stakeholders expressed a need for more effective prevention education in schools, beginning at younger ages.

- c. Stakeholders felt that children may experience a disconnect between the prevention education they received at school and seeing their families use drugs in their homes or in their neighborhoods.
 - i. Participants expressed that law enforcement did not address community drug issues in an effective manner by focusing on convictions rather than public health.
- d. Social media and the influence of peers who smoke, drink, or use other substances illegally could influence children to model the behavior.

6. Health and Oral Health Care Access, Cost, and Insurance (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Stakeholders thought both access to care and insurance coverage were better for children compared to adults.
- b. Differential access to health and oral health care was noted between rural and urban areas.
- c. Stakeholders reported a shortage of specialty health and oral health service providers for children broadly but especially for children and youth with special health care needs (CYSHCN) and especially in rural areas.
- d. Participants also noted difficulty accessing primary care for their children due to scheduling and wait lists. Caregivers also noted that appointments felt too short, with limited time service providers could spend with their child.
- e. Participants shared that they struggle with Medicaid not providing coverage for pediatric orthodontia.

7. Health and Developmental Screening (*identified in the following Data Collection Methods: F, K, S*)

- a. Overall, developmental screening levels were low relative to national averages.
- b. Family survey respondents reported differences in health and developmental screenings based on the age of the child.
- c. Key informants noted some improvements particularly related to funding for screening and service provider education around screening.
- d. Younger children were more likely to have had developmental and hearing screenings, older children were more likely to have had vision screenings, and there were minimal differences in other health screenings.

III. Statements of needs: Child Domain

In considering the quantitative FAD and qualitative data presented above, 10 statements describing areas of need in the child health domain were developed and presented to community stakeholders and agency leadership for discussion and prioritization. A more detailed description of the prioritization process may be found on pages 19-22 of the executive summary.

The statements, as well as their prioritized rank after the process was completed, are listed in the table below.

RANK	Potential Priority Need/Issue
1 (tie)	Lack of timely, appropriate, and consistent health and developmental screenings
1 (tie)	Lack of access to quality early childhood programs that are safe and affordable, especially for children with disabilities
3	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
4	High levels and worsening trends for childhood obesity
5	Lack of or inadequate substance abuse treatment (smoking, alcohol, and drugs) and prevention education, including detox, addiction, and rehabilitation/recovery services
6	Lack of or inadequate smoking, alcohol, and substance use prevention education
7	Lack of or inadequate access to mental health services that are comprehensive and age-appropriate
8	Lack of comprehensive, family-centered, and culturally competent health care
9	Lack of supports for pregnant and parenting teens and young/new parents

These rankings, alongside the rankings of identified areas of need in other domains, were then considered holistically in order to reach the final 10 needs across all Title V populations. These are listed on page 26 of the executive summary.

ADPH 2020 Title V Maternal and Child Health Services Block Grant Comprehensive Needs Assessment Domain Report: Adolescent

I. Setting a Baseline for Adolescent Health in Alabama: A Summary of Federally Available Data

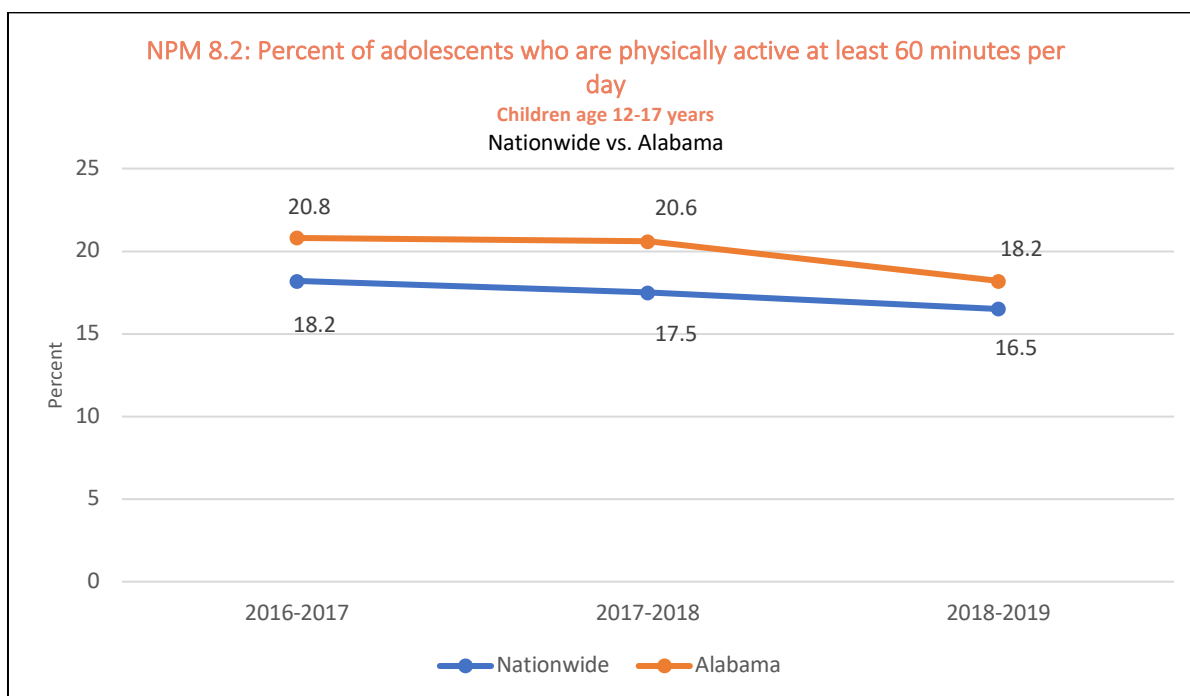
Each state is provided with a set of indicators that cover all Title V domains. These indicators are tied to the National Performance Measures and National Outcome Measures on which states have chosen to focus. The table below summarizes all of the indicators that are associated with adolescent health for Alabama. Note: Some data were unavailable for examination across time due to changes in collection strategies at the federal level.

Adolescent Health Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Physical activity (12-17 years, every day)	20.6%	Better	Trending worse
Bullying (victimization)	19.6%	About the same	About the same
Adolescent well-visit	76.3%	About the same	About the same
Preventive dental visit – adolescent	88.0%	Better	About the same
Adolescent mortality	46.9 per 100,000	Worse	About the same
Adolescent motor vehicle death	25 per 100,000	Worse	Trending better
Adolescent suicide	9.1 per 100,000	Better	Trending worse
HPV vaccination	58.0%	Worse	Trending better
Obesity – ages 10-17	18.2%	Worse	Trending worse
Teen births	27.0 per 1,000	Worse	Trending better

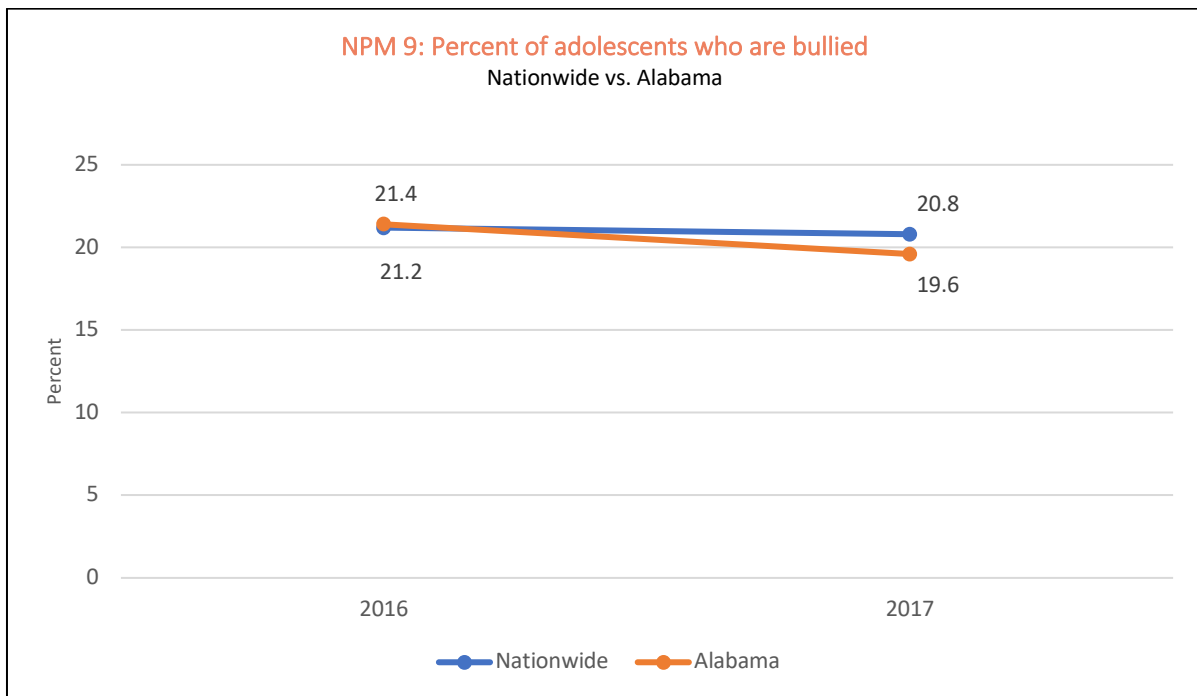
*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arrears. See page 3 for information on FAD and to access current information.

In keeping with the guiding principle of promoting health equity and reducing disparities, several areas of disparity were noted across all domains in both the Federally Available Data (FAD) and qualitative findings. For this domain, indicator data show differences in outcomes based on race, ethnicity, and socioeconomic status. Furthermore, these inequities are driven by many factors, including social determinants of health like education, poverty, structural racism, and housing safety and quality. Notable disparities in sentinel indicators are also presented below in conjunction with the indicators' Alabama-U.S. comparisons.

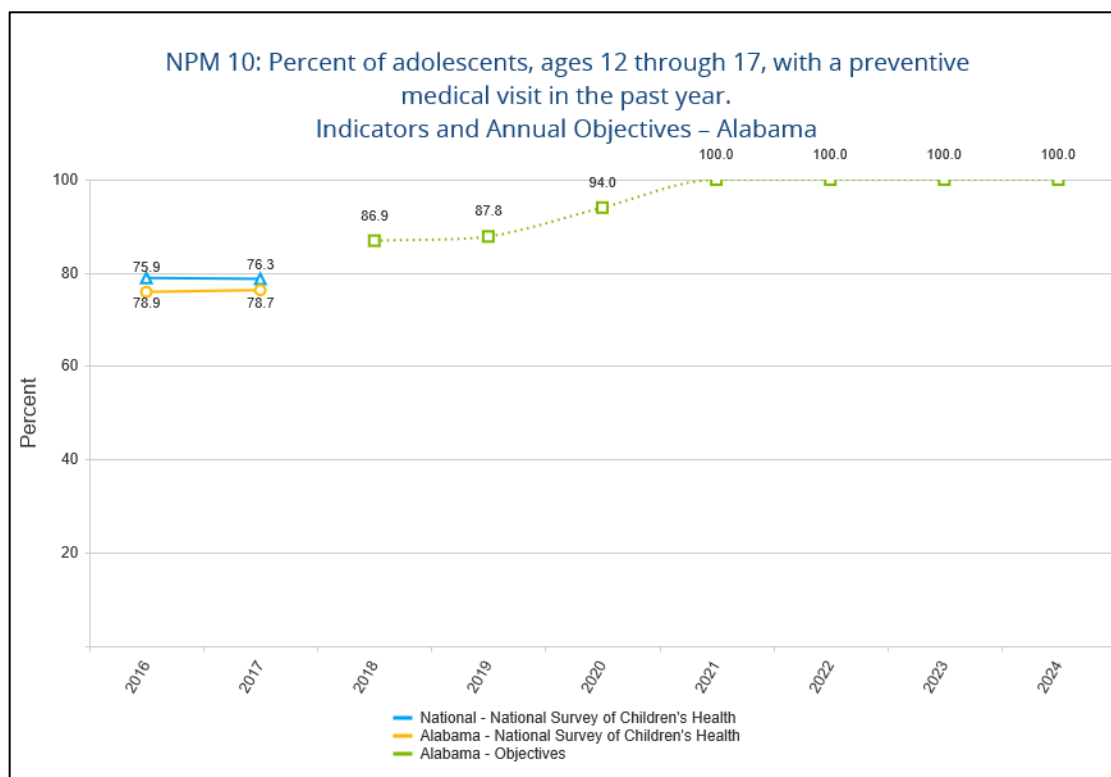
The following charts present the above data in more detailed form and, where available, across time to show comparisons to national indicators and trends.



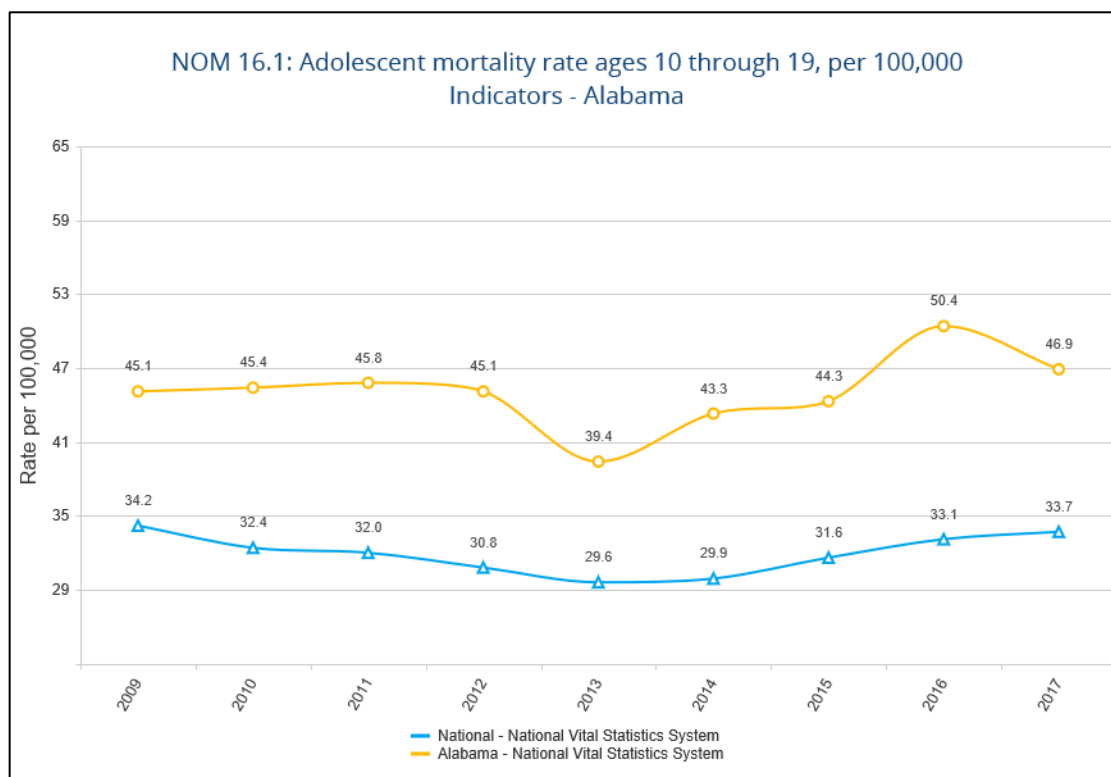
The above data, from the National Survey of Children's Health, compares Alabama and the U.S. on NPM 8.2 (Percent of adolescents who are physically active at least 60 minutes per day, children aged 12-17 years). Comparisons must be made using pooled data from two survey years due to small sample sizes. Across the three survey iterations, both Alabama and nationwide percentages have seen a slight decline. Alabama percentages have been slightly higher than the nationwide percentages.



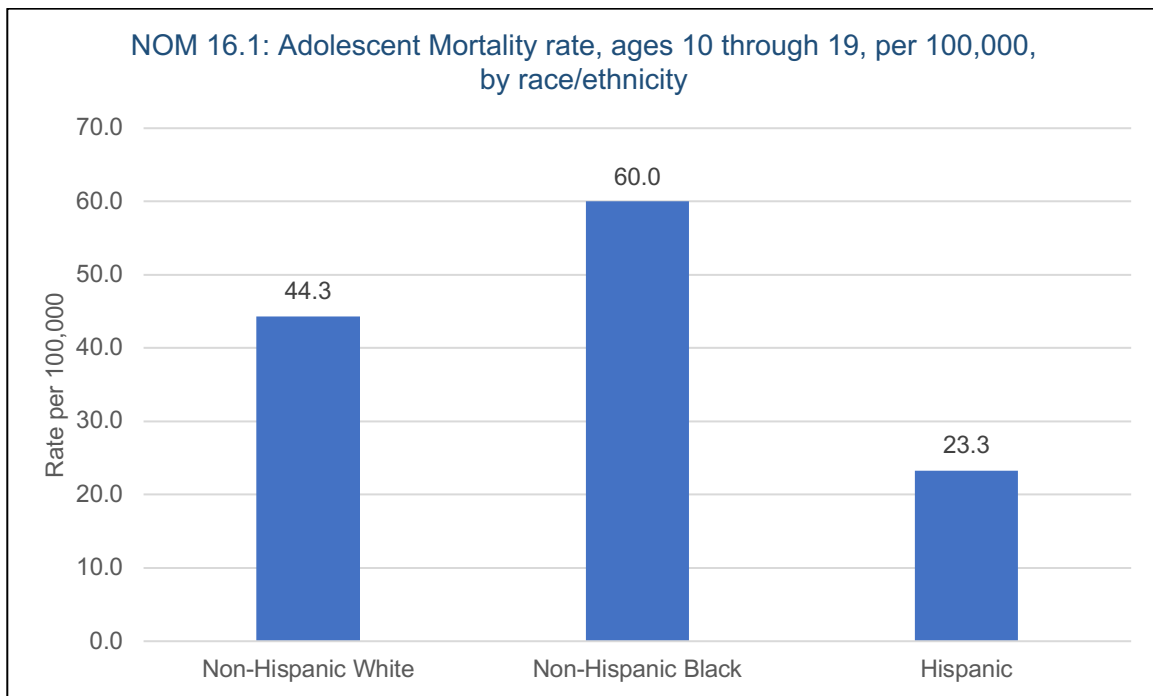
The above data, from the 2016 and 2017 National Survey of Children’s Health, compare Alabama and the U.S. on NPM 9 (Percent of adolescents who are bullied). Approximately one in five adolescents report being bullied. Alabama and nationwide percentages have been similar to one another and fairly stable across the two survey years.



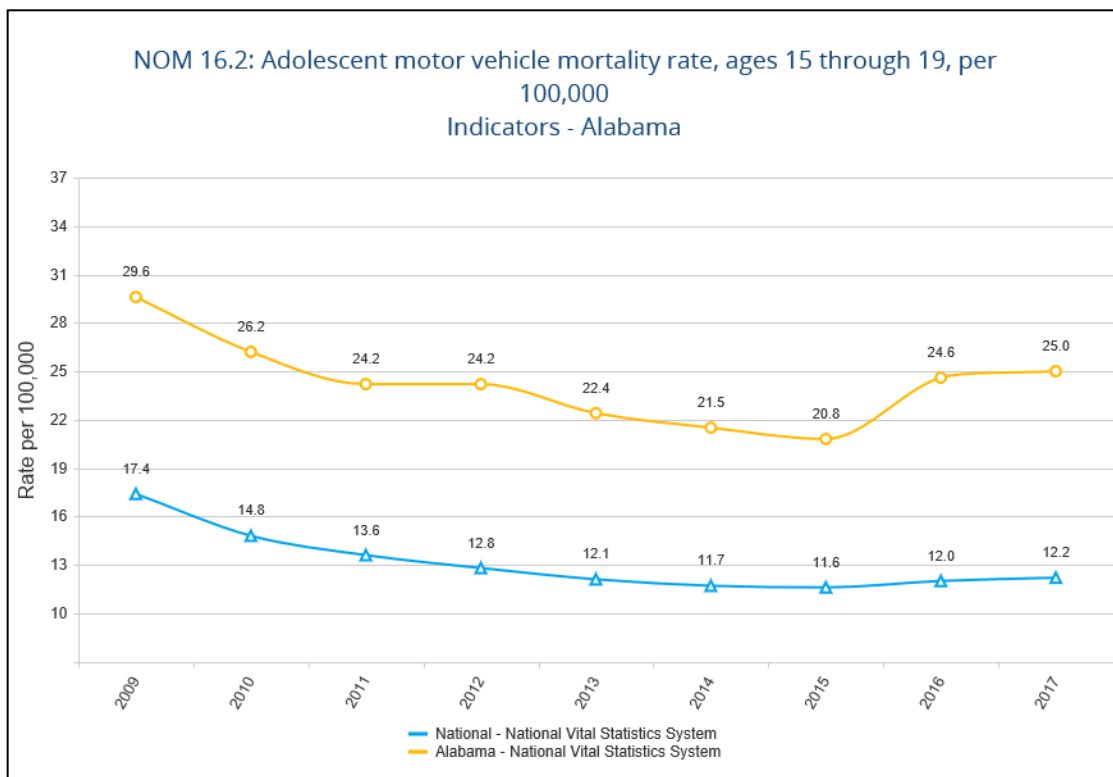
The above data, from the 2016 and 2017 National Surveys of Children’s Health, compare Alabama and the U.S. on NPM 10 (Percent of adolescents, ages 12-17, with a preventative medical visit in the past year). Over the two years of available data, Alabama’s average is similar to the national average and remains steady from year to year.



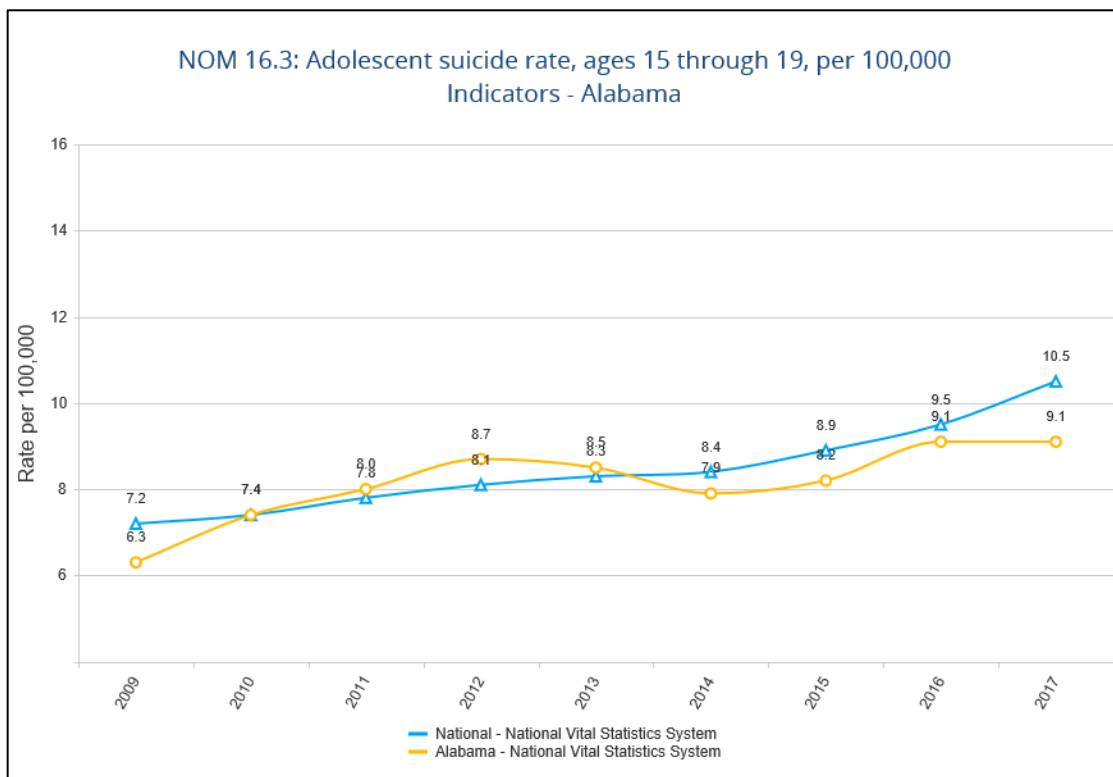
The above data, from the National Vital Statistics System from years 2009 to 2017, compare Alabama and the U.S. on NOM 16.1 (Adolescent mortality rate ages 10-19, per 100,000). Alabama's rate stayed relatively steady between 2009 and 2012 before dropping in 2013. The rate rose again until 2016. It fell to a rate similar to that of 2009-2012 in 2017. Alabama has stayed well above the national rate for adolescent mortality despite relative improvements from 2012-2013 and 2016-2017.



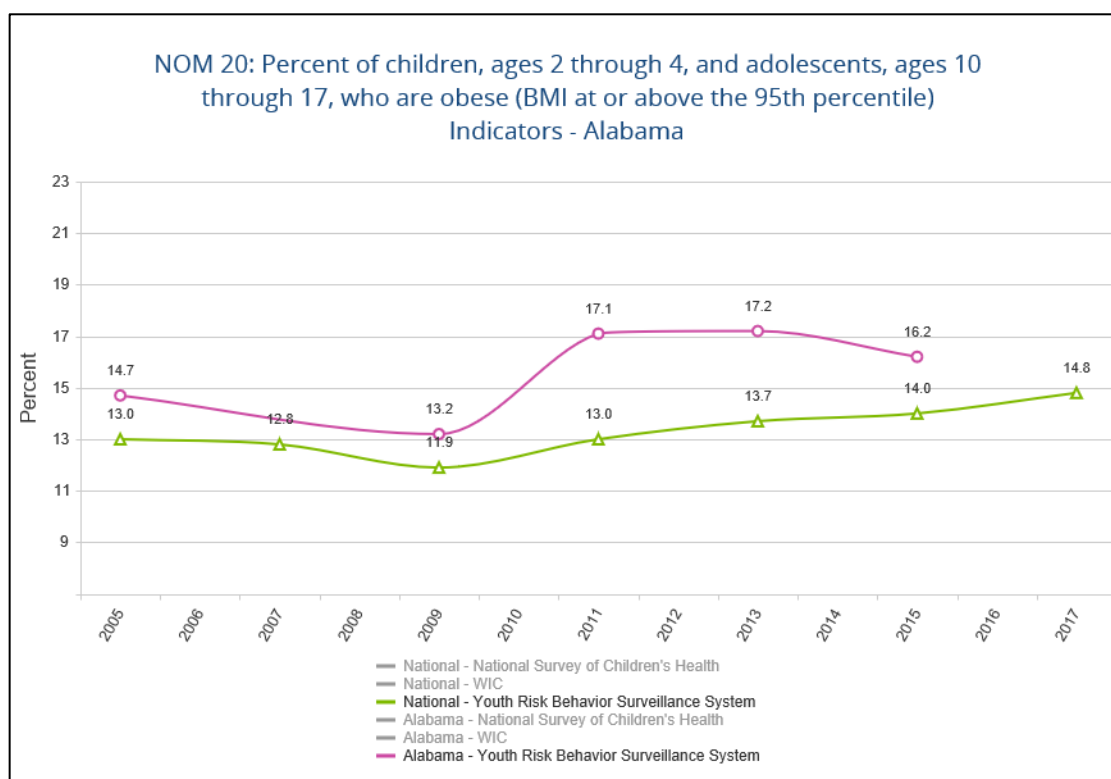
This chart presents disparities in the adolescent mortality by race and ethnicity according to the most recent National Vital Statistics System data (2017). The highest adolescent mortality rate was among Non-Hispanic Black adolescents (60.0 per 100,000). The lowest mortality rate was among Hispanic adolescents (23.3 per 100,000).



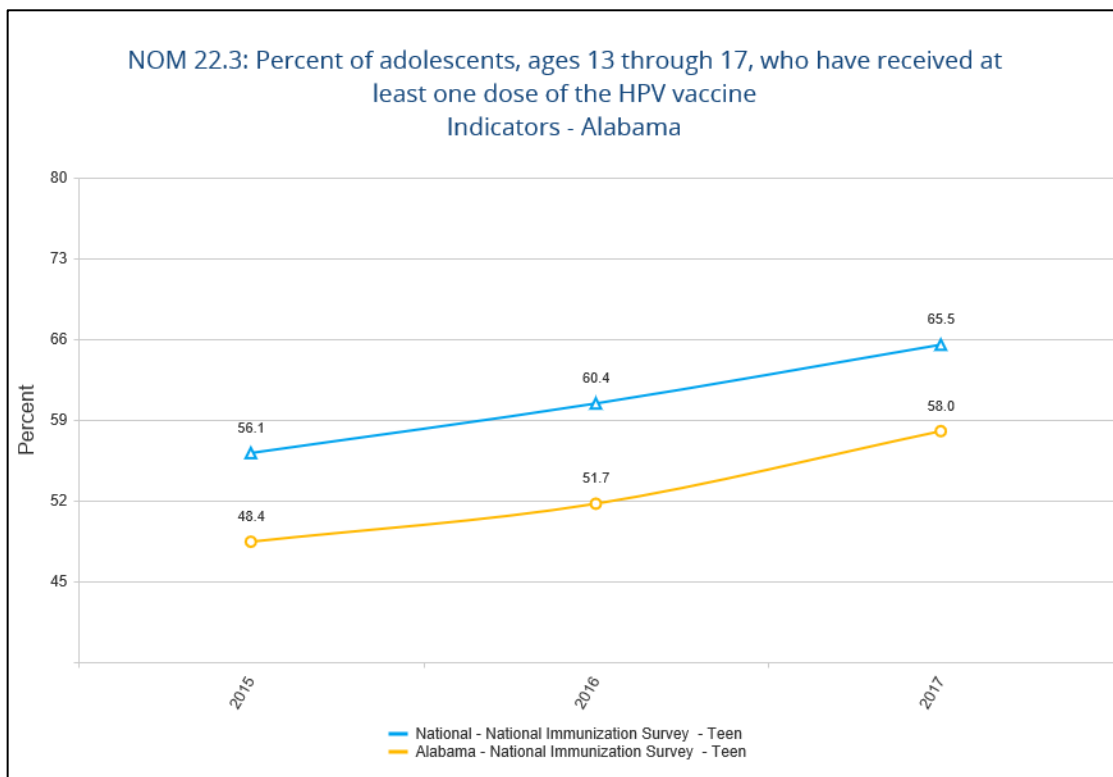
The above data, from the National Vital Statistics System from years 2009 to 2017, compare Alabama and the U.S. on NOM 16.2 (Adolescent motor vehicle mortality rate, ages 15 through 19 per 100,000). Alabama's rate is consistently around twice that of the national average. While the U.S. has been slowly declining since 2009, Alabama followed the same trajectory until 2015. There was an increase in the rate in 2016, holding consistent through 2017. Alabama's rate in 2016 and 2017, while higher than the years immediately preceding, is nonetheless lower than rates at the beginning of the available years of data.



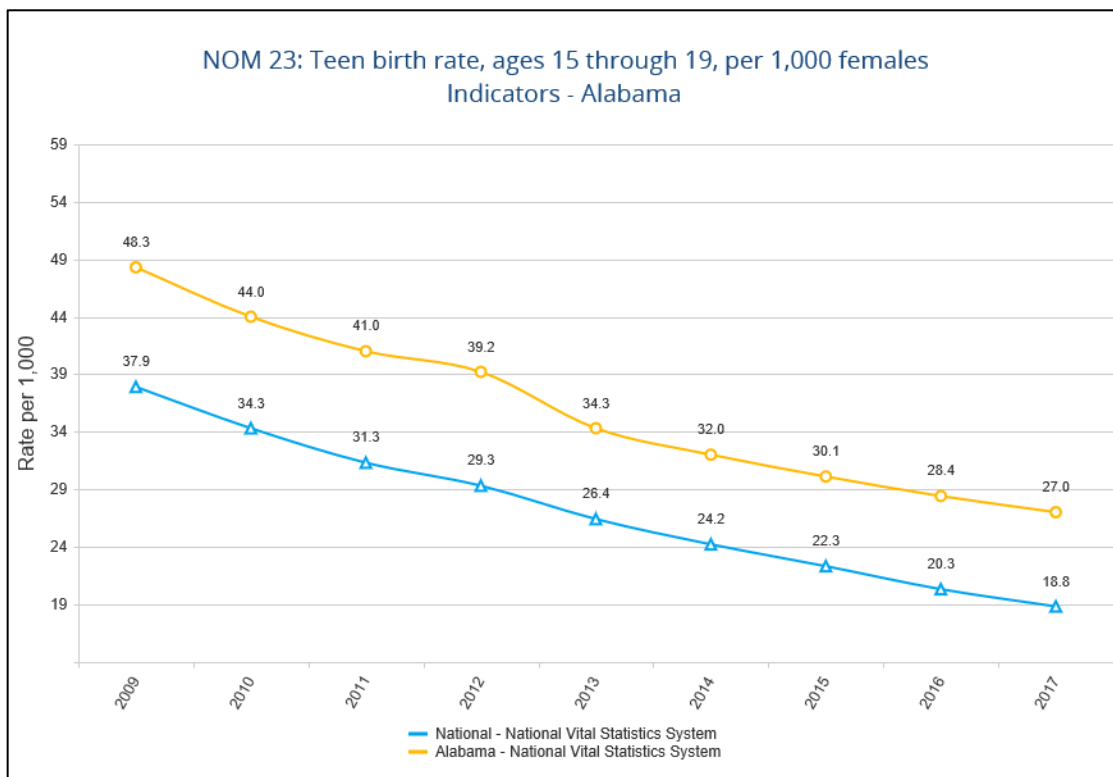
The above data from the National Vital Statistics System from 2009 to 2017 compare Alabama and the U.S. on NOM 16.3 (Adolescent suicide rate, ages 15 through 19, per 100,000). Alabama's rate has fluctuated relative to the consistent increase in the national data; however, since 2014, Alabama's rates have been lower than the national average. These data, however, reveal an overall worsening trend.



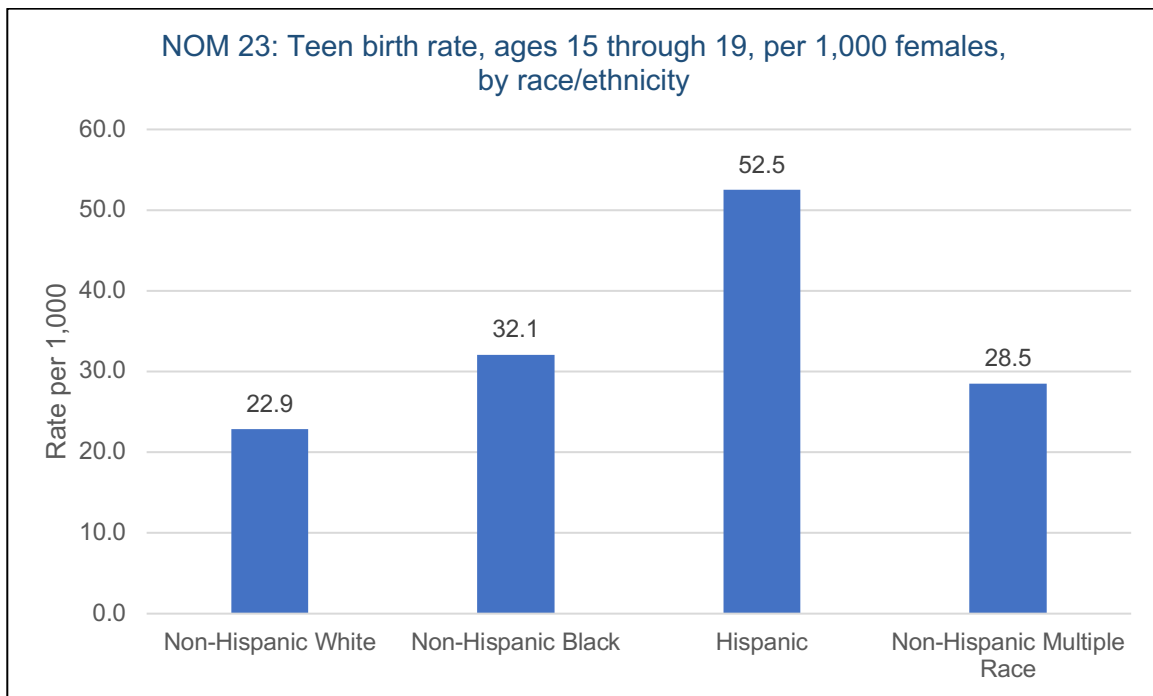
The above data, from the Youth Risk Behavior Surveillance System from the years 2009 to 2017 (National) and 2009 to 2015 (Alabama), compare Alabama and the U.S. on NOM 20 (Percent of children, ages 2 through 4, and adolescents, ages 10 through 17, who are obese [BMI at or above the 95th percentile]). Alabama's percentage is consistently higher than national data, though data indicate an overall improvement for Alabama while the national average is worsening.



The above data, from the National Immunization Survey (Teen) for 2015 through 2017, compare Alabama and the U.S. on NOM 22.3 (Percent of adolescents, ages 13 through 17, who have received at least one dose of the HPV vaccine). While Alabama's percentage has remained lower than the national average in all available years, there is an overall trend towards improvement.



The above data from the National Vital Statistics System from years 2009 to 2017 compare Alabama and the U.S. on NOM 23 [Teen birth rate, ages 15 through 19, per 1,000 females) between the years of 2009 and 2017. Alabama's rates have been consistently higher than the national average; however, both Alabama and the U.S. have seen large decreases in the rates since 2009.



This chart presents the disparities in the teen birth rate by race and ethnicity according to the most recent National Vital Statistics System data (2017). Hispanic teens reported the highest teen birth rate (52.5 per 1,000). Non-Hispanic White teens reported the lowest birth rate (22.9 per 1,000).

II. Themes from Survey and Qualitative Findings

In an effort to gain more detailed information around community experiences, preferences, concerns, and perceptions, a series of focus groups, key informant interviews, and surveys (including a specific adolescent-focused survey) were conducted in late 2019.

Focus group transcripts, key informant interview notes, and survey responses were analyzed to identify common themes across data collection methods and broad stakeholder populations. A more detailed description of the data analysis may be found on pages 3-5 of the executive summary.

Thorough analyses identified six broad themes that describe the adolescent health environment in Alabama. These are described below, along with the method or methods that yielded the supporting evidence for each theme.

Legend for Data Collection Method and Abbreviation

Data Collection Method	Abbreviation
Federally Available Data	F
Focus Groups	G
Key Informant Interviews	K
Surveys	S

1. Pregnant and Parenting Teens (*identified in the following Data Collection Methods: G, K, S*)

- Teen parents reported a lack of access to parenting education, guidance, and mentorship, leading to feelings of being unprepared to care for their children.
- Focus group and interview participants believed teens who are pregnant suffer from a lack of guidance and mentorship that may lead to infant deaths. Cell phone use and other distractions while parenting may also contribute to infant mortality.
- Teen parents needed mental health support, especially postpartum.

2. Reproductive and Sexual Health Education (*identified in the following Data Collection Methods: G, K, S*)

- Reproductive and sexual health education has become less comprehensive in recent years. Focus group and interview participants reported wanting the following topics covered in school-based sex education: pregnancy, sexually transmitted infections (STIs), and family planning (including but not limited to abstinence).
- School-based programs should be more comprehensive, including discussion of pregnancy, STIs, and family planning (including abstinence and contraception options).
- School-based programs should begin at younger ages.
- Parents wanted resources so that they could effectively discuss sexual health with their children.

- e. Focus group participants noted a desire for respectful communication and education from their health care service providers.

3. Adolescent Mental Health (*identified in the following Data Collection Methods: G, K, S, F*)

- a. Adolescents faced a number of mental health crises that were unique to this population including bullying, gun violence, and suicide.
- b. It was difficult for parents and caretakers to navigate the mental health care system and learn what services are available for youth with mental health care needs.
- c. Unmet mental health needs and emotional issues, including depression and low self-esteem, may lead to substance abuse.

4. Adolescent Smoking, Substance, and Alcohol Use (*identified in the following Data Collection Methods: G, S*)

- a. Vaping, synthetic marijuana, marijuana, and alcohol consumption were the substances described as commonly used by adolescents.
- b. Smoking, vaping, and smokeless tobacco usage had the highest percentage of ratings as “big problem” on the adolescent survey.
- c. Family and peers played an important role as adolescents often chose to engage in substance use if they saw it in their homes and communities.
- d. Participants identified a need for more comprehensive and effective school-based prevention education.
- e. Safe recreation was limited in many communities and possibly contributed to adolescent drug use being more common.
- f. Some participants were concerned about teenagers and substance use during pregnancy leading to infant deaths.

5. Physical Activity (*identified in the following Data Collection Methods: S, K, F*)

- a. Physical activity was limited among adolescents. Nearly 60% of adolescent survey respondents reported exercising 30 minutes per day for fewer than 5 days per week, and nearly 1 in 5 reported no days at all.

6. Supports for Transitioning to Adulthood (*identified in the following Data Collection Methods: S, F*)

- a. Adolescents need trusted adult role models and mentors; some adolescents perceived they did not have these.
- b. Adolescents wanted to have more agency in dealing with health care service providers.
- c. Adolescents wanted better preparation, information, and resources to support them in handling “real world” adult issues, including finding a job, going to college, learning to manage finances/budgeting, and accessing health care.

III. Statements of needs: Adolescent Domain

In considering the quantitative FAD and qualitative data presented above, 10 statements describing areas of need in the adolescent health domain were developed and presented to community stakeholders and agency leadership for discussion and prioritization. A more detailed description of the prioritization process may be found on pages 19-22 of the executive summary.

The statements, as well as their prioritized rank after the process was completed, are listed in the table below.

RANK	Potential Priority Need/Issue
1	Inequitable access to health resources based on race/ethnicity, socioeconomic status, geographic location, and education
2	Lack of or inadequate access to mental health services that are comprehensive and age-appropriate
3	Lack of supports for pregnant and parenting teens
4	Lack of or inadequate substance abuse treatment (smoking, alcohol, drugs) and prevention education
5	Discrimination, bias, and differences in quality of care based on race/ethnicity, socioeconomic status, marital status, age, insurance status/type, sexual orientation, and gender identity
6	Inadequate and insufficient health and sexual health education
7	Lack of or inadequate access to comprehensive reproductive health care, including for LGBTQ populations and adolescents with disabilities
8	Inadequate or insufficient preparation, information, and resources to support transition to adulthood
9	Lack of or inadequate access to affordable and safe options for physical activity, exercise, and recreation
10	Limited access to adult role models and mentors

These rankings, alongside the rankings of identified areas of need in other domains, were then considered holistically in order to reach the final ten needs across all Title V populations. These are listed on page 26 of the executive summary.

ADPH 2020 Title V Maternal and Child Health Services Block Grant Comprehensive Needs Assessment

Domain Report: Children and Youth with Special Health Care Needs (CYSHCN)

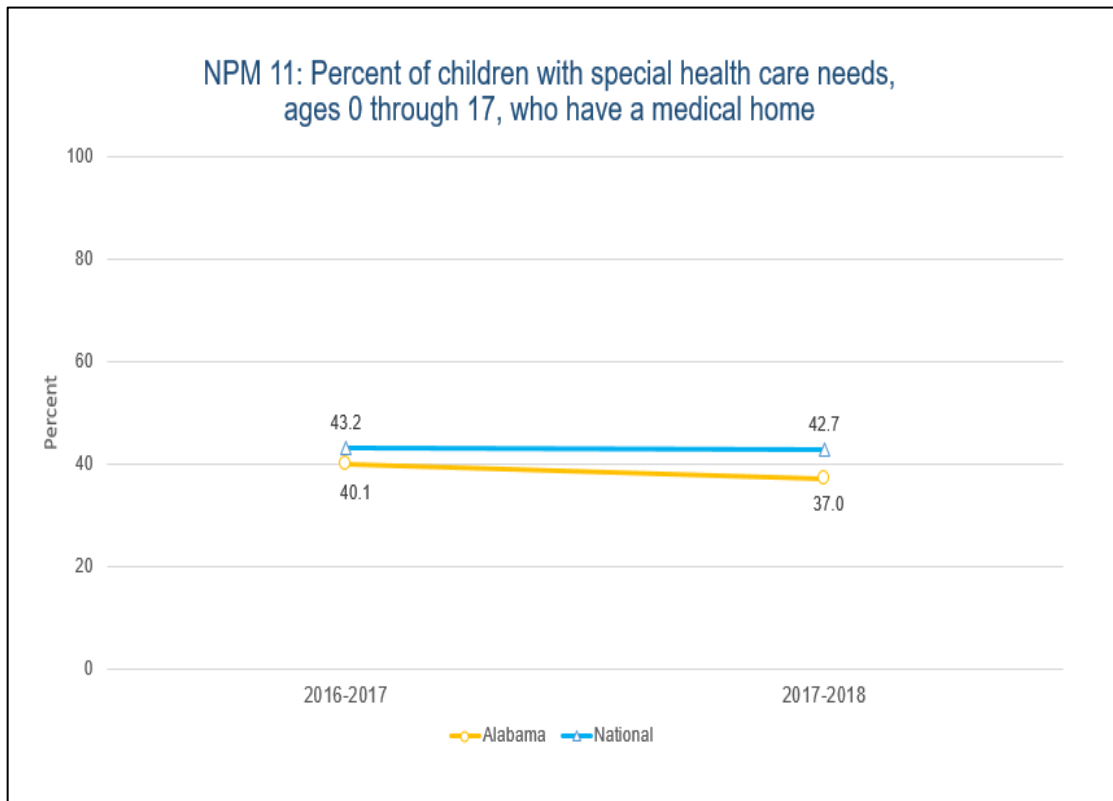
I. Setting a Baseline for CYSHCN in Alabama: A Summary of Federally Available Data

Each state is provided with a set of indicators that cover all Title V domains. These indicators are tied to the National Performance Measures and National Outcome Measures on which states have chosen to focus. The table below summarizes all of the indicators that are associated with CYSHCN in Alabama based on data from the National Survey of Children's Health. Note: Examination of trends across time are somewhat limited due to changes in data collection strategies at the federal level and availability of only two data points.

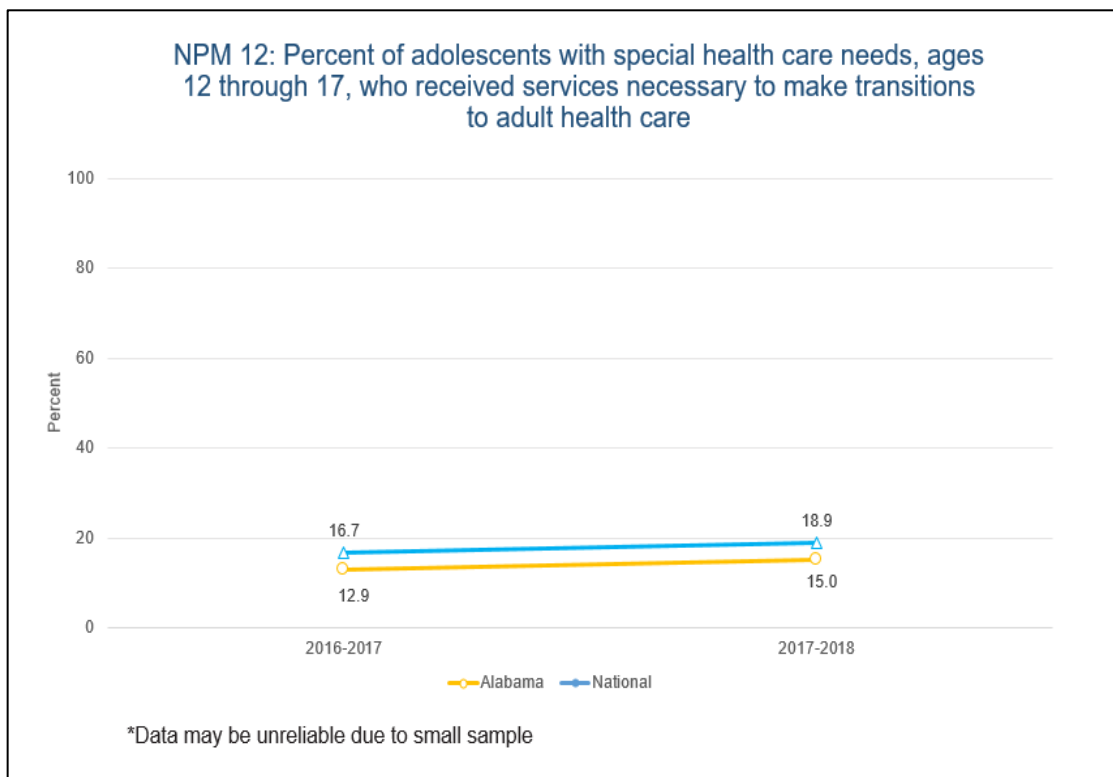
CYSHCN Indicators	Most Recently Available Value*	How does Alabama compare to the U.S.?	How has Alabama been doing?
Medical home	37.0%	Slightly worse	Trending slightly worse
Transition	15.0%	Slightly worse	Trending slightly better
Adequate insurance	64.2%	Slightly better	Trending slightly worse
CYSHCN systems of care (received all components of a well-functioning system: family partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition)	16.3%	Slightly better	Trending slightly worse

*Most recently available value as of March 2020. Actual dates may vary as data are often reported in arears. See pages 3 and 6 for information on FAD and to access current information.

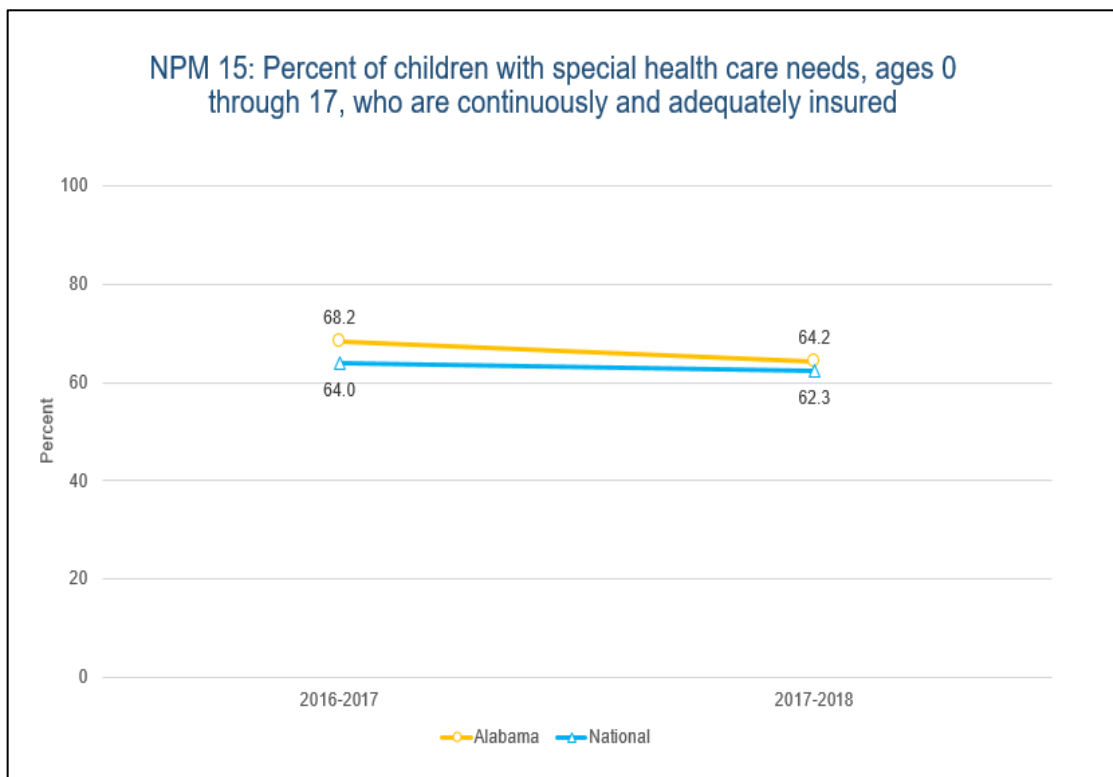
The following charts present the above data in more detailed form and, where available, across time to show comparisons to national indicators and trends. Small sample sizes preclude stratifying state CYSHCN data to identify disparities in outcomes based on socio-demographic factors.



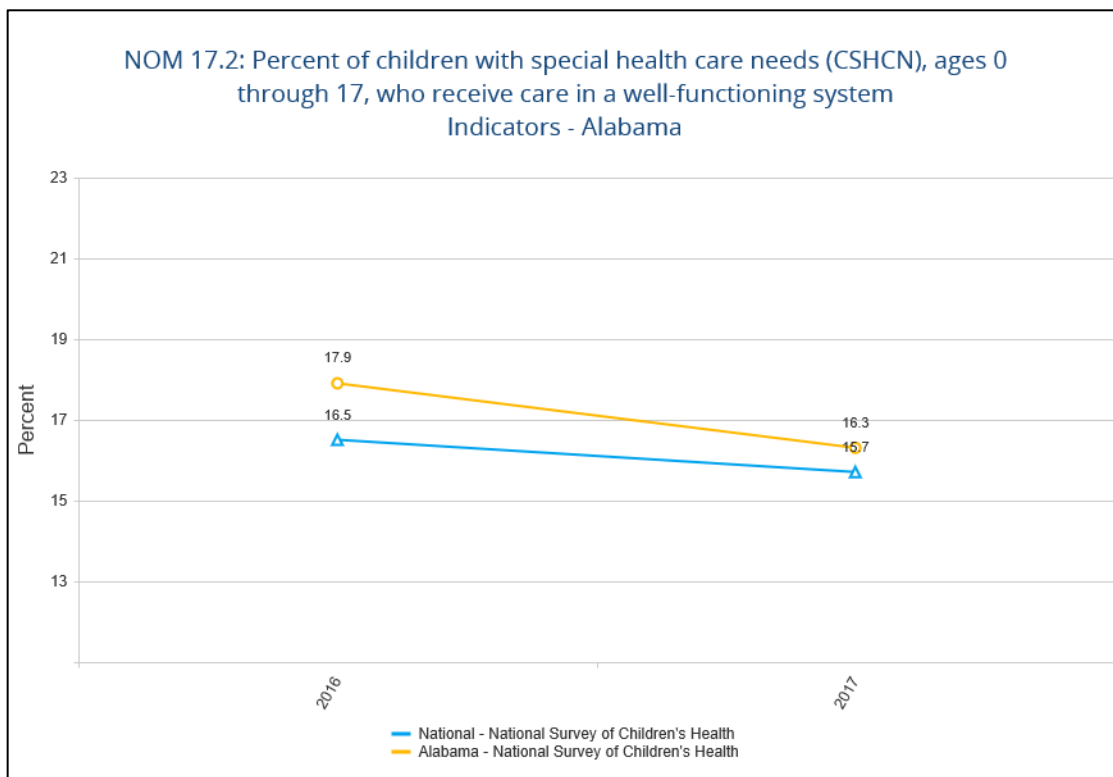
The above data compare Alabama and the U.S. on NPM 11 (Percent of children with special health care needs, ages 0 through 17, who have a medical home) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. For the two reporting periods included above, Alabama reported lower percentages of CYSHCN who have a medical home compared to the national data. Both Alabama and the U.S. are trending slightly worse over the two reporting periods, with Alabama experiencing a slightly sharper decline. Though this chart displays outcomes for CYSHCN only, data are also available for non-CYSHCN. There is very little difference for this measure between CYSHCN and non-CYSHCN.



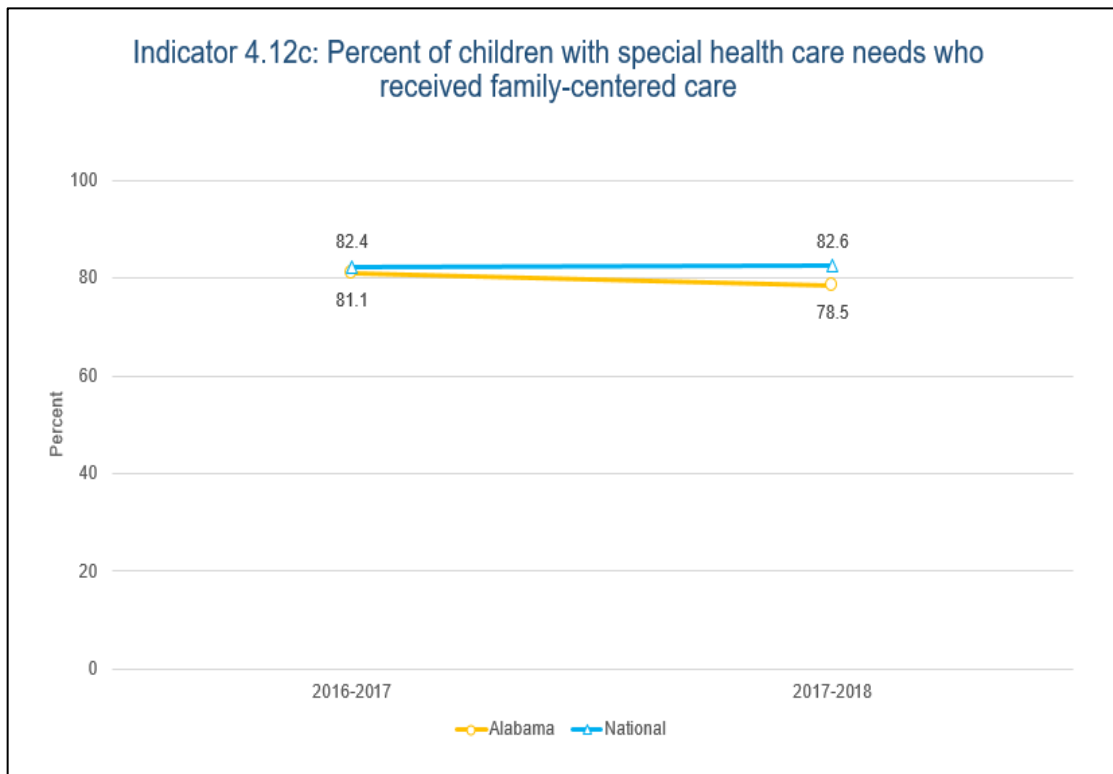
The above data compare Alabama and the U.S. on NPM 12 (Percent of adolescents with special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. For the two reporting periods included above, Alabama reported lower percentages of CYSHCN who have a medical home compared to the national data. Both Alabama and the U.S. are trending slightly better over the two reporting periods, with percentages increasing. These data may be unreliable due to the small sample size of adolescents with SHCNs at the state level. This measure is low for both CYSHCN and non-CYSHCN, but a much smaller percentage of CYSHCN meet this measure compared to adolescents without SHCN.



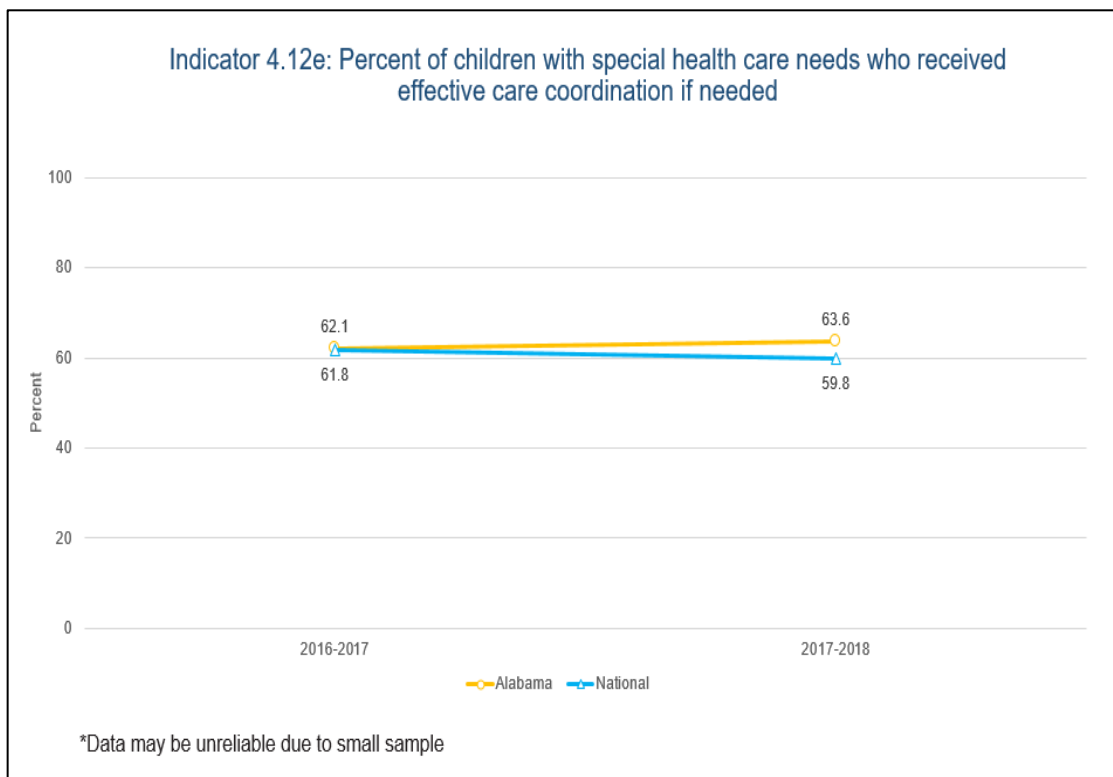
The above data compare Alabama and the U.S. on NPM 15 (Percent of children with special health care needs, ages 0 through 17, who are continuously and adequately insured) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. For the two reporting periods included above, Alabama reported percentages higher than the national percentages. Both Alabama and the U.S. are trending slightly worse over the two reporting periods, with Alabama experiencing a slightly sharper decline. A smaller percentage of CYSHCN meet this measure compared to adolescents without SHCN.



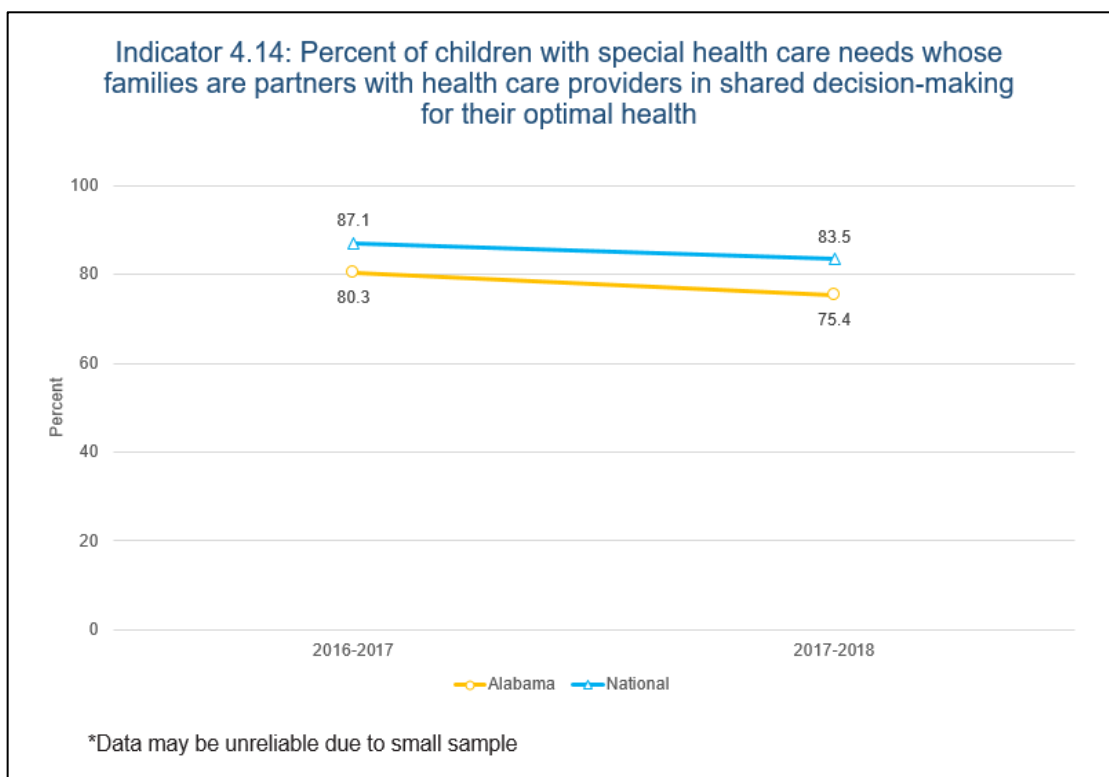
The above data compare Alabama and the U.S. on NPM 17.2 (Percent of children with special health care needs, ages 0 through 17, who receive care in a well-functioning system) between 2016 and 2017. Alabama reported percentages higher than the national percentages. Both Alabama and the U.S. are trending slightly worse over the reporting period, with Alabama experiencing a slightly sharper decline.



The above data compare Alabama and the U.S. on indicator 4.12c (Percent of children with special health care needs who received family-centered care) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. For the two reporting periods included above, Alabama reported percentages lower than the national percentages. Though national percentages have remained relatively stable over the two years, Alabama is trending slightly worse. A smaller percentage of families with CYSHCN meet this measure compared to families without CYSHCN.



The above data compare Alabama and the U.S. on indicator 4.12e (Percent of children with special health care needs who received effective care coordination if needed) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. Alabama reported percentages higher than the national percentages, especially for the second reporting period. While the nation is trending slightly worse over the two reporting periods, Alabama is trending slightly better. A smaller percentage of families with CYSHCN meet this measure compared to families without CYSHCN.



The above data compare Alabama and the U.S. on indicator 4.14 (Percent of children with special health care needs whose families are partners with health care providers in shared decision-making for their optimal health) between 2016 and 2018. Comparisons must be made using pooled data from two survey years due to small sample sizes. Alabama reported percentages lower than the national percentages. Both Alabama and the nation are trending slightly worse over the two reporting periods, with the percentages dropping for both. According to the most recent data, more than 7 in 10 Alabama families with CYSHCN partner in shared decision-making with health care providers. A smaller percentage of families with CYSHCN meet this measure compared to families without CYSHCN.

II. Themes from Survey and Qualitative Findings

In an effort to gain more detailed information around community experiences, preferences, concerns, and perceptions, a series of focus groups, key informant interviews, and surveys (including a specific adolescent-focused survey) were conducted in late 2019.

Focus group transcripts, key informant interview notes, and survey responses were analyzed to identify common themes across data collection methods and broad stakeholder populations. A more detailed description of the data analysis may be found on pages 6-8 of the executive summary.

Thorough analyses identified 14 broad themes that describe the health environment of CYSHCN in Alabama. These are described below, along with the data collection method that yielded the supporting evidence for each theme.

Legend for Data Collection Method and Abbreviation

Data Collection Method	Abbreviation
Federally Available Data	F
Focus Groups	G
Key Informant Interviews	K
Surveys	S

1. Access to Care and Quality of Services (*identified in the following Data Collection Methods: S*)

- a. Families reported a variety of health care and related services that were challenging to access or were unsatisfactory when accessed. The services most commonly reported as unable to get or were dissatisfied with service:
 - i. Mental Health/Behavioral Health
 - ii. Specialty Care
 - iii. Occupational Therapy
 - iv. Speech Therapy
- b. When asked why they experienced difficulty accessing services, families most commonly reported the following reasons:
 - i. Providers not available
 - ii. Did not know where to go/who to see
 - iii. Waiting list for services too long
 - iv. Insurance didn't cover services or providers
 - v. State policy or administrative barriers

2. Lack of Transportation (*identified in the following Data Collection Methods: G, K, S*)

- a. Service providers and some families, especially in rural areas, frequently reported a lack of transportation as a barrier to accessing care.
 - i. This can often lead to missed appointments for care and therapies.
- b. This included high gas prices, limited access to vehicles, unreliable and inadequate public transportation.

3. Difficulty finding convenient and qualified providers (*identified in the following Data Collection Methods: G, K, S*)

- a. Stakeholders reported a workforce shortage, especially for service providers knowledgeable about CYSHCN and specific diagnoses.
- b. Access to services is limited by travel time, personal and office schedules, and distance to service providers.
- c. Concentration of specialty services and programs in urban settings and limited availability in rural areas pose barriers to access.

4. Inadequate Insurance Coverage and Cost (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Caregivers wanted to provide their children with high quality services and supports, but coverage limitations and high out-of-pocket costs often made it difficult or impossible to do so.
 - i. Limited coverage of specific types and amount of services and visit frequency were major drivers of this.
 - ii. Families also experienced difficulties accessing affordable specialty equipment, limits on insurance timeframes for purchasing new equipment, and significant out-of-pocket costs.
- b. Limited or lost coverage and benefits (equipment/services) after age 21 was a major concern for families.
- c. There was a limited number of primary and sub-specialty service providers accepting Medicaid.
 - i. Families perceive the quality of service providers that do accept Medicaid as worse than the quality of service providers that do not accept Medicaid.

5. Strict Program Qualifications (*identified in the following Data Collection Methods: G, K, S*)

- a. Rigid administrative criteria to qualify for programs limits access.
- b. There were long wait lists for services, especially Medicaid waivers.
- c. There was a lack of information regarding the qualification criteria for Medicaid waivers.

6. Access to Community-Based Services (*identified in the following Data Collection Methods: G, K, S*)

- a. Families reported a variety of community services that were challenging to access or were unsatisfactory when accessed. The services most commonly reported as unable to get or were dissatisfied with service:
 - i. Child Care/Day Care
 - ii. After School Care
 - iii. Summer/Out-Of-School Care
 - iv. Recreational Opportunities
 - v. Special Education
 - vi. Care Coordination
- b. When asked why they experienced difficulty accessing services, families most commonly reported the following reasons:
 - i. Providers not available
 - ii. Did not know where to go/who to see
 - iii. Waiting list for services too long
 - iv. Insurance didn't cover services or providers
 - v. State policy or administrative barriers
- c. Other barriers to community service access:
 - i. Discussions were similar to those presented under access to health and health-related services
 - ii. Recreational and extracurricular activities existed in some areas of the state but were, overall, not meeting needs; programs lacked knowledge or were uncomfortable working with CYSHCN.
 - iii. Expanded discussions focused on child care, special education, and family supports

7. Accessibility and Accommodations (*identified in the following Data Collection Methods: G, K, S*)

- a. There were limited accessibility accommodations in the general community environment.
 - i. Doorways were too small for wheelchairs, there was a lack of ramps, and unsafe walkways were present in some areas.
 - ii. Caregivers noted a lack of adult size changing tables in public restrooms.
 - 1. Weight limits for child diaper-changing tables in public facilities caused caregivers to have to change their child on the bathroom floor or take them home.
 - iii. Youth with SHCN expressed concerns about lack of accessibility and accommodations during health appointments (physical accessibility, tables, scales, etc.).
- b. There were language barriers, and interpreter services were inconsistently available.
 - i. The lack of Spanish-speaking interpreters across the system of care and/or delays in appointments while waiting for an interpreter can impact quality of care.

- ii. There was a shortage of sign language interpreters.
- c. Accessibility of health information and administrative materials:
 - i. Materials and forms were poorly translated.
 - ii. There was a shortage of materials for people who are blind or have low vision.

8. Safe, Affordable, and Inclusive Childcare and Preschool Programs (*identified in the following Data Collection Methods: G, K, S*)

- a. Caregivers wanted safe, affordable, quality childcare options, especially for young children.
 - i. This included day care, after school care, respite, and summer/out-of-school programs.
- b. Parents wanted more training for teachers and childcare workers and better accessibility to these services in their communities for children with disabilities and special needs.

9. Transition to Adulthood and Adult Health Care (*identified in the following Data Collection Methods: F, G, K, S*)

- a. Transition planning was inadequate or inconsistent.
 - i. Families reported a lack of conversation and guidance around transition planning.
 - 1. Families had to identify resources for themselves.
 - ii. Families said the approach to transitioning to adult-based care was often not holistic and usually focused solely on one aspect of adulthood.
- b. Adult health care services were challenging to access or inaccessible.
 - i. Adult services and services after turning age 21 were limited or non-existent, especially from service providers knowledgeable about SHCN.
 - ii. Out-of-pocket costs increased sharply after age 21 due to lack of coverage for services.
 - iii. Youth needed and wanted supports to manage their medical conditions as independently as possible.
- c. Meaningful employment opportunities were limited.
 - i. Caregivers and youth with SHCN wanted meaningful employment to support financial security, independent living, community inclusion, and a sense of purpose/accomplishment.
 - ii. More supports were needed for building job skills; supports should start when children are younger.
- d. Independent living was the goal for many families.
 - i. Families reported a desire for their CYSHCN to live independently but were concerned about what would happen when “they were no longer around”.
 - 1. Families felt that, without appropriate supports, their CYSHCN would be unable to live independently.
 - ii. Youth with SHCN expressed the desire to live independently and have freedom to make their own choices.
- e. Community services for adults were limited.

- i. Families were concerned about what their children would do with their time when they were no longer in the school system.
 - ii. Many caregivers of transition age youth and adults discussed the service drop-off following graduating from the school system and were unable to locate services that could provide support and intervention specific to their needs.
- f. Evidence-based and developmentally appropriate reproductive and sexual health education and education around pregnancy and parenting were necessary.
 - i. Some service providers may not realize that youth with disabilities are sexually active and that having a disability does not prevent an individual from parenting capably.
 - ii. CYSHCN were interested in romantic relationships and dating and needed accurate information about these activities.
 - iii. Young women with disabilities wanted education tailored toward getting pregnant and parenting with a disability (breastfeeding, carrying an infant).

10. Family Supports and Respite Care (identified in the following Data Collection Methods: G, K, S)

- a. Caregiver stress placed significant mental burdens on families including siblings of CYSHCN.
 - i. The large amount of time and energy needed to coordinate and advocate for their child around medical care, education, and day-to-day needs was exhausting for parents and caregivers.
 - ii. Families reported difficulties planning for outings in the community for errands or family fun/community events and may avoid these activities for fear of lack of accessibility, accommodations, and inclusion.
 - iii. Caregivers had mental health care needs.
 - 1. Accessibility to these services was limited.
 - 2. Families may avoid reaching out due to stigma, guilt, or the additional time, cost, and system navigation effort required.
- b. Family dynamics were impacted by CYSHCN.
 - i. Having a CYSHCN affected relationships with other children and spouses.
 - ii. Extended family members provided significant support to CYSHCN and their families.
- c. Parent and peer-to-peer support was critical.
 - i. Support and connection with other parents/caregivers was essential to finding support and services.
 - ii. This connection alleviated feelings of isolation and loneliness.
 - iii. Families reported that the most helpful information they received was from networking with parents or individual research.
 - 1. Facebook and Google were frequently used resources.
 - iv. There was recognized value in connecting with other families that have previously navigated the system and can provide guidance and assistance.
- d. Safe and high quality respite care was inadequate, inconsistent, or unavailable in the community.
 - i. Caregivers reported difficulty accessing services.

- ii. The amount of time available was very limited.
- iii. Caregivers wanted more visits/hours and availability across a larger geographic distribution.

11. Special Education (*identified in the following Data Collection Methods: G, K, S*)

- a. The Individualized Education Program (IEP) process caused anxiety and confusion.
 - i. Families noted that the IEP process was tedious, tension-filled, confusing and burdensome; qualifications for services was difficult to navigate, often resulting in limited frequency of services.
 - ii. Families reported high levels of dissatisfaction with the transition process in the school system.
- b. Limited resources in schools lead to inadequate services.
 - i. Families noted limited funding for special education programs and services.
 - ii. Many families stated their child was not receiving quality services and intervention at the frequency necessary due to limited resources in some districts.
 - 1. Families noted inequities across different school systems.
 - iii. Families noted issues with limited resources resulting in low compensation for teachers, aides, and therapists leading to high turnover rates.
 - 1. This resulted in inconsistencies for their child and a loss of highly qualified professionals.
- c. Inclusion in educational settings was not meeting the needs or desires of families.
 - i. Families expressed a lack of inclusion with typically developing peers in certain educational settings.
 - ii. Families feared their child was not challenged at school and that limited exposure to typically developing peers may result in a lack of social skills development.
- d. Information about the special education process and systems was confusing and complicated.
 - i. Families expressed limited understanding of the special education process.
 - ii. Families felt knowledge and information was not adequately explained or interpreted to them, resulting in feelings of disconnection from their child's education.
 - iii. Families noted a lack of information and understanding regarding special education law.

12. Navigation of System of Care (*identified in the following Data Collection Methods: F, G, K, S*)

- a. System navigation was often overwhelming for families.
 - i. Families reported immense difficulty navigating across systems that provide services to their CYSHCN and family.
 - ii. Families noted the need to be proactive when interacting with the system of care in order to have needs met.
 - iii. Families reported general confusion about the system, increased time to navigate, bureaucracy, and language and cultural barriers.

- iv. Families experienced stigma based on race/ethnicity, public insurance, receipt of government benefits, and disability status.
- b. Families desired education, information, and communication about the system of care for their CYSHCN.
 - i. Families needed additional support, facilitation, and training for navigating the system.
 - ii. Families wanted to be more aware of the services and programs available for their CYSHCN.
 - 1. They especially wanted information related to eligibility criteria.
 - iii. Families felt that services across all sectors were disjointed. This placed the burden of communication between services and service providers on them.
 - iv. Families expressed frustration regarding delayed diagnoses due to communication barriers across systems.
 - v. Families expressed the need for communication among primary and sub-specialty care service providers and the school system.
- c. Continuity of care coordination was wanted.
 - i. Families highlighted the need for care coordination throughout the lifespan, including the health care and education system.
 - ii. This process should begin earlier than it currently does, according to key informants.
 - iii. Some families said that challenges are rooted in a lack of awareness or knowledge about what care coordination is and the availability of service.

13. Technology, Electronic Medical Records, and Lack of Data (*identified in the following Data Collection Methods: G, K, S*)

- a. Service providers reported lack of integrated medical record systems and technology, which limited continuity of care.
- b. There were limited Federally Available Data (FAD) specific to CYSHCN at the state level.
- c. Other state programmatic data specific to disability and special health care needs are limited.

14. Healthy Behaviors (*identified in the following Data Collection Methods: S*)

- a. Youth with SHCN reported very limited regular physical activity (even when not reporting major physical limitations).
- b. Youth with SHCN reported infrequently eating fruits and vegetables.
- c. Youth with SHCN reported primarily sedentary recreational activities.

III. Statements of needs: CYSHCN Domain

In considering the quantitative FAD and qualitative data presented above, 15 statements describing areas of need in the CYSHCN health domain were developed and presented to community stakeholders and agency leadership for discussion and prioritization. A more detailed description of the prioritization process may be found on pages 22-25 of the executive summary.

The statements, as well as their prioritized rank after the process was completed, are listed in the table below.

RANK	Potential Priority Need/Issue
1	Insufficient special education services
2	Lack of or inadequate access to health and related services, especially in rural areas and for services identified as difficult to obtain
3	Inadequate insurance, including cost and benefit coverage issues
4	Lack of or inadequate supports for transition to all aspects of adulthood
5 (tie)	Lack of or inadequate access to comprehensive medical homes
5 (tie)	Lack of or inadequate transportation for accessing health and community services
7	Support shared decision-making and partnerships between families and health-related professionals
8	Increase family and youth involvement and participation in advisory groups, program development, policymaking, and system-building activities
9	Lack of provider workforce that is knowledgeable about CYSHCN, especially in rural areas and for adult services
10 (tie)	Lack of or inadequate access to community services and supports, especially in rural areas and for services identified as difficult to obtain
10 (tie)	Lack of access to quality early childhood programs that are safe and affordable, especially for children with disabilities
12	Lack of or inadequate accessibility and accommodation supports, including physical environment, interpreter services, and materials
13	Lack of integrated technology, medical records, and data to support continuity of care and data-informed decision-making for program planning and evaluation
14	Youth with SHCN are not meeting guidelines for physical activity and nutrition
15	Inadequate assistance for families – especially those who are new to the state, whose first language is not English, and who have a child with a new diagnosis – to navigate the system of care, including identifying providers, family supports, and community resources

CRS leadership selected the following top three prioritized needs based on a second-phase, consensus-based prioritization strategy:

1. Lack of or inadequate supports for transition to all aspects of adulthood
2. Lack of or inadequate access to health and related services, especially in rural areas and for services identified as difficult to obtain
3. Increase family and youth involvement and participation in advisory groups, program development, policymaking, and system-building activities

These statements, alongside the rankings of identified areas of need in other domains, were then considered holistically in order to reach the final 10 needs across all Title V populations. These are listed on page 26 of the executive summary.

Appendix 1. Acronyms and Abbreviated Names

<u>Acronym/Name</u>	<u>Explanation</u>
ADPH	Alabama Department of Public Health
ADRS	Alabama Department of Rehabilitation Services
AEAC	Applied Evaluation and Assessment Center, UAB SOPH
All Kids	Alabama's State Children's Health Insurance Program
BCBS	Blue Cross and Blue Shield of Alabama
BFHS	Bureau of Family Health Services
Block Grant	MCH Title V Block Grant to States Program
BMI	Body Mass Index
BRFSS	Behavioral Risk Factor Surveillance System
CDC	U.S. Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
CRS	Children's Rehabilitation Service
CYSHCN	Children and Youth with Special Health Care Needs
DHR	Alabama Department of Human Resources
ESM	Evidence-based or -informed Strategy Measures
FAD	Federally Available Data
FVA	Family Voices of Alabama
GED	General Educational Development
HPV	Human Papilloma Virus
HRSA	U.S. Health Resources and Services Administration
IEP	Individualized Education Program
LGBTQ/LGBTQ+	Lesbian, Gay, Bisexual, Transgender, or Questioning, inclusive of all statuses
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MCH Epi Branch	Maternal and Child Health Epidemiology Branch (located in BFHS)
Medicaid	Alabama Medicaid Agency
NAS	Neonatal Abstinence Syndrome
NICU	Neonatal Intensive Care Unit
NOM	National Outcome Measure
NPM	National Performance Measure
PRAMS	Pregnancy Risk Assessment Monitoring System
SHCN	Special Health Care Needs
SIDS	Sudden Infant Death Syndrome
SOM	State Outcome Measure
SOPH	School of Public Health
SPM	State Performance Measure
State	State of Alabama
STIs	Sexually Transmitted Infections
SUID	Sudden Unexpected Infant Death
Title V	MCH Title V
Tricare	Health care program of the U.S. Department of Defense Military Health System
TVIS	Title V Information System
UAB	University of Alabama at Birmingham
U.S.	United States of America
VLBW	Very Low Birth Weight
VRS	Vocational Rehabilitation Service
WIC	Special Supplemental Nutrition Program for Women, Infants and Children
YRBSS	Youth Risk Behavior Survey System
YSHCN	Youth with Special Health Care Needs

Appendix 2. Socio-Demographics of Focus Group Participants and Family and Adolescent Survey Respondents: Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains

Demographics of Focus Group Participants: Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains

Characteristic	Number	Percent
Gender		
Female	133	90%
Male	10	7%
Other	2	1%
Race		
Black or African American	73	51%
White	62	44%
Other*/Two or more races	9	6%
Ethnicity		
Not-Hispanic or Latino	118	82%
Hispanic or Latino	26	18%
Marital Status		
Single/Never Married	60	42%
Married	59	41%
Separated/Divorced/Widowed	25	17%
Highest Level of Education Completed		
Less than high school	18	12%
High school/GED	44	30%
Some college	31	21%
2-year college degree	20	14%
4-year college degree	20	14%
Graduate/Professional degree	13	10%
Total Household Income		
Less than \$10,000	56	40%
\$10,000 to \$19,999	25	18%
\$20,000 to \$29,999	12	9%
\$30,000 to \$39,999	10	7%
\$40,000 to \$49,999	9	6%
\$50,000 or more	29	21%
Disability Status		
Does Not have a Disability	113	80%
Has a Disability	21	21%
Children in the Household		
Yes	118	84%
No	23	16%

*Other includes American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and Asian

Demographics of Family Survey Respondents: Women/Maternal, Perinatal/Infant, Child, and Adolescent Domains

Characteristic	Number	Percent
Gender		
Female	752	97%
Male	26	3%
Race		
Black or African American	225	29%
White	474	62%
Other*/Two or more races	69	9%
Ethnicity		
Not-Hispanic or Latino	860	87%
Hispanic or Latino	124	13%
Marital Status		
Single/Never Married	316	41%
Married	331	43%
Separated/Divorced/Widowed	124	17%
Household Health Insurance Status		
All individuals have insurance	686	77%
One or more individuals uninsured	206	23%
Highest Level of Education Completed		
Less than high school	42	6%
High school/GED	237	31%
Some college	182	24%
2-year college degree	95	12%
4-year college degree	132	17%
Graduate/Professional degree	73	10%
Total Household Income		
Less than \$10,000	141	23%
\$10,000 to \$19,999	91	15%
\$20,000 to \$29,999	78	13%
\$30,000 to \$39,999	62	10%
\$40,000 to \$49,999	39	6%
\$50,000 to \$59,999	29	5%
\$60,000 to 69,999	30	5%
\$70,000 or more	149	25%
Disability Status		
Does Not have a Disability	660	83%
Has a Disability	132	17%
Age		
21 years and younger	64	9%
22 to 30 years	233	32%
31 to 40 years	233	32%
41 to 50 years	100	14%
51 years and older	87	12%
<i>Mean = 35 Range = 16-75</i>		
Type of Survey Taken		
Paper	570	58%
Online	414	42%

*Other includes American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and Asian

Demographics of Adolescent Survey Respondents: Adolescent Domain

Characteristic	Number	Percent
Gender		
Female	65	76%
Male	21	24%
Race/Ethnicity		
Black or African American	39	45%
White	38	44%
Hispanic	5	6%
Other*/Two or more races	5	6%
Type of Health Insurance		
No Insurance	6	7%
Medicaid or Medicare	20	23%
All-Kids	5	6%
Private Insurance	46	53%
TRICARE	4	5%
I don't know	5	6%
Age		
Younger adolescent: 13 to 17 years	44	51%
Older adolescent: 18 to 24 years	42	49%

*Other includes American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and Asian

Appendix 3. Socio-Demographics of Focus Group Participants and Family and Youth Survey Respondents: Children and Youth with Special Health Care Needs (CYSHCN) Domain

Demographics of Focus Group Participants: CYSHCN Domain

Characteristic	Number	Percent
Participant		
Mother	10	38%
Father	7	27%
Grandparent	4	15%
Youth	5	19%
Race/Ethnicity		
Black or African American	9	35%
White	12	46%
Hispanic or Latino	5	19%
Highest Level of Education Completed		
Less than high school	4	15%
High school/GED	2	8%
Some college	8	31%
Vocational Training /Trade School/2-year college degree	6	23%
4-year college degree or higher	6	23%
Total Household Income		
Less than \$30,000	3	17%
\$30,000 to \$39,999	2	11%
\$40,000 to \$49,999	1	6%
\$50,000 to \$59,999	3	17%
\$60,000 to \$69,999	3	17%
\$70,000 or more	6	33%

Demographics of Family Survey Respondents: CYSHCN Domain

Characteristic	Number	Percent
Relationship to CYSHCN		
Mother	268	81%
Father	24	7%
Grandparent	27	8%
Other	13	4%
Race/Ethnicity		
Black or African American	111	34%
White	192	58%
Hispanic or Latino	19	6%
Other*	13	4%
Survey Language		
English	274	95%
Spanish	13	5%
Highest Level of Education Completed		
Less than high school	41	13%
High school/GED	84	27%
Some college	60	19%
Vocational Training /Trade School/2-year college degree	54	17%
4-year college degree or higher	77	24%
Number of CYSHCN in the Household		
1	363	83%
2	58	13%
3	13	3%
4+	2	<1%
Ages of CYSHCN		
Birth to 3 years	61	14%
4 to 9 years	146	33%
10 to 13 years	90	21%
14 to 17 years	73	17%
18 to 20 years	46	11%
21 to 26 years	20	5%
Type of Survey Taken		
Paper	287	69%
Online	129	31%

*Other includes American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and Asian

Demographics of Youth Survey Respondents: CYSHCN Domain

Characteristic	Number	Percent
Gender		
Female	72	43%
Male	56	56%
Prefer to self-describe	1	1%
Race/Ethnicity		
Black or African American	51	38%
White	73	54%
Hispanic	4	3%
Other*/Two or more races	5	4%
Type of Health Insurance		
No Insurance	8	5%
Medicaid or Medicare	83	57%
All-Kids	3	2%
Private Insurance	42	29%
TRICARE	4	3%
Other/I don't know	6	4%
Age		
12 years old or younger	19	15%
13 to 17 years	45	34%
18 to 21 years	51	40%
22-26 years	6	5%
Older than 26 years	10	8%
Highest Level of School Completed		
Still in middle school	27	22%
Still in high school	41	33%
Left high school without a diploma	2	2%
Received a high school diploma/GED	29	24%
Some college, but left and did not graduate	6	5%
Still in college	11	9%
Vocational Training /Trade School/2-year college degree	0	0%
4-year college degree or higher	7	6%

*Other includes American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and Asian

Alabama's Title V Maternal and Child Health (MCH) Needs Assessment was led by staff from the Bureau of Family Health Services at the Alabama Department of Public Health (ADPH).

Title V Director

Amanda Martin, MSPH

Deputy Director

Bureau of Family Health Services
Alabama Department of Public Health
amanda.martin@adph.state.al.us

Title V Children with Special Health Care Needs Director

Cathy Caldwell, MPH

Assistant Commissioner

Children's Rehabilitation Service
Alabama Department of Rehabilitation Services
cathy.caldwell@rehab.alabama.gov

Title V MCH Block Grant Coordinator

Tammie Yeldell, BS, MPH

Director, MCH Epidemiology Branch
Alabama Department of Public Health
tammie.yeldell@adph.state.al.us

*For any additional questions about the Alabama Needs Assessment,
please contact Tammie Yeldell.*

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Julie Preskitt, MSOT, MPH, PhD

Associate Professor

Director of the Applied Evaluation and Assessment Collaborative

Anne E. Brisendine, DrPH, CHES

Science Director

Applied Evaluation and Assessment Collaborative

Beth Johns, OTR/L, MPH

Senior Project Director

Applied Evaluation and Assessment Collaborative

Elizabeth L. Blunck, MPH

Program Manager

Applied Evaluation and Assessment Collaborative

Elizabeth Taylor, MSW, MPH

Program Manager

Applied Evaluation and Assessment Collaborative

Evelyn Coronado-Guillaumet, MPH

Consultant

Honour McDaniel

MPH Student

Martha S. Wingate, MPH, DrPH

Professor and Chair

Health Care Organization and Policy

Applied Evaluation
and Assessment Collaborative

 THE UNIVERSITY OF ALABAMA AT BIRMINGHAM



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PUBLIC HEALTH

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM