

Title V Maternal and Child Health 2020 Needs Assessment, Data Brief 6

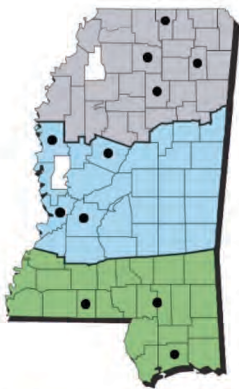
Children and Youth with Special Health Care Needs Domain



MISSISSIPPI
STATE DEPARTMENT OF HEALTH

This data brief is one of a six-part series that describes the methods and findings from Mississippi's 2020 Title V Maternal and Child Health Needs Assessment. For more information on Title V Maternal and Child Health and needs assessment, please see Data Brief 1: 2020 Needs Assessment Overview and Methods. Additional data briefs in the series present findings for other maternal and child health population domains.

How did we collect information?



The Mississippi State Department of Health partnered with the Applied Evaluation and Assessment Center at the University of Alabama at Birmingham (UAB) School of Public Health to conduct the 2020 needs assessment. UAB collaborated with The University of Southern Mississippi Institute for Disability Studies, Mississippi Community Education Center, and the Family Resource Center of North Mississippi to promote needs assessment activities. Needs assessment methods encouraged broad stakeholder engagement and included focus groups, key informant interviews, surveys, and analysis of Federally Available Data.

All elements of the data collection plan were designed to be accessible and encourage participation from a diverse population.

- Focus group locations

Colors indicate counties from which responses were received and are categorized by public health region.

Broad Stakeholder Engagement

Federally Available Data	Surveys					Focus Groups		Key Informant Interviews
	Maternal and Child Health (online)	Healthcare providers (online)	Adolescents (online)	YSHCN (online and paper)	Families of CYSHCN (online and paper)	Women Parents/caregivers of infants, children, and adolescents Adolescents/young adults		Representatives of local, state, public, and private group that work with MCH population
Key MCH indicators provided to states	577	104	58 (176 total)	62	167	11 groups	75 participants	20 interviewees
Total stakeholders engaged: 1,239								

*Some respondents did not meet age established range for adolescents; these responses were analyzed with the general Maternal and Child Health survey.

Health Equity and Disparities

Promoting equity and reducing disparities in outcomes are core values for the Mississippi State Department of Health and the Title V MCH Needs Assessment. National indicator data show differences in outcomes based on child/youth's race, ethnicity, socioeconomic status, age, and type of insurance. Stakeholders expressed differences in access to services, treatment experiences, and perception of quality of care based on geographic location, race, ethnicity, socioeconomic status, primary language, disability status, and insurance type. Health disparities not only affect groups facing inequities, but also limit overall improvements in quality of care and the health status for the broader population, resulting in unnecessary costs. All Mississippians benefit when we promote equity and reduce disparities through policies, practices, and organizational systems.

2020 Needs Assessment: CYSHCN Health

▶ What We Learned: Identified Needs



Lack of or inadequate supports for transition to all aspects of adulthood

- After age 19, coverage and benefits are lost or limited for many YSHCN.
- Adult services are limited or non-existent after YSHCN are no longer served in a pediatric or school-based setting.
- It is difficult to access disability insurance for supplemental income.
- There is a lack of conversation and guidance around transition planning.
- The approach to transitioning to adult-based care is often not holistic and focuses on one aspect of transition to adulthood.
- Education, resources, and programs are needed to help YSHCN successfully transition to adulthood.
- YSHCN may have limited to no conversations with their health care provider regarding access to adult based health care and limited encouragement from their provider to take responsibility for their health-related needs (i.e., taking medication, understanding their health condition).
- YSHCN report limited engagement with their provider

at health-related appointments, but noted feeling involved and included in health care decisions.

- YSHCN desire to finish high school/obtain their GED, getting and keeping health insurance and engagement in social relationships.



Inadequate insurance, including cost and benefit coverage issues

- Some services are difficult to access. Services most commonly reported as unable to get or dissatisfied with were:
 - o mental and behavioral health
 - o oral health
 - o occupational therapy
 - o speech therapy
- Most commonly reported reasons for difficulty accessing service providers were:
 - o services were not covered by insurance
 - o services were too expensive,
 - o waiting list for services too long
 - o did not know where to go/ who to see
 - o providers knowledgeable about CYSHCN and specific diagnoses were unavailable
- Some equipment is difficult to access. The most commonly reported reason for difficulty accessing this equipment

was that it is not covered by insurance.

- Equipment most commonly reported as unable to get or were dissatisfied with was:
 - o eyeglass/contacts
 - o hearing aids
 - o specialty and mobility equipment
- It is difficult to access disability insurance for supplemental income.
- YSHCN desire to have and maintain health insurance coverage.



Lack of or inadequate access to health and related services, especially in rural areas and for services identified as difficult to obtain

- The concentration of specialty services and programs is in urban areas. There is limited availability of providers in rural areas. Travel time, appointment availability, and caretakers' work schedules further limit access to providers.
- Lack of transportation is a barrier to accessing health care, especially in rural areas.
- Receiving a diagnosis for a child and accessing appropriate services is difficult for caregivers due to the length of process and complexity.

2020 Needs Assessment: CYSHCN Health



Lack of or inadequate access to coordinated, comprehensive care

- Services across all sectors are fragmented and that they are responsible for communication between their child's providers.
- CYSHCN do not have access to a Shared Plan of Care to aid in communication across systems.
- Care coordination is needed throughout the lifespan, including the health care and education systems, to support caregivers and provide resources. Communication among primary care and specialty providers and the school system is necessary.
- Providers expressed frustration with the lack of/inadequate follow-up care provided to CYSHCN and their families.



Lack of or inadequate support for family/caregiver wellbeing

- Families experience high rates of caregiver stress related to the time, energy, and financial costs of coordinating and advocating for their child around health care, education, and other day-to-day considerations.

- Caregivers identified a need for high quality and affordable parent support from the community. Knowledge of available services and the ability to access more support services should be expanded.
- Having a CYSHCN affects family dynamics and relationships within families for siblings and spouses.
- Extended family members provide significant support, including respite care, to CYSHCN and their families.



Inadequate support for caregivers navigating the system of care

- It is difficult for caregivers to navigate across systems that provide services to their CYSHCN. Delayed diagnoses and intervention because of communication barriers across systems is frustrating.
- Barriers included:
 - general confusion about the system
 - bureaucracy
 - lack of care coordination and support available to families of CYSHCN.
- Immigrant communities may not have knowledge of available resources and have an even greater need for help navigating the health care system.



Lack of or inadequate access to CYSHCN-specific health education

- The following topics are of interest to caregivers of CYSHCN:
 - information about their child's diagnosis
 - career/employment opportunities
 - developing an emergency preparedness plan
 - healthy behaviors
 - recreational activities
 - finding an adult health care provider
- General health education should be tailored to meet the needs of CYSHCN and their caregivers.
- Latinx/Immigrant communities may have limited awareness of and additional needs for education around disabilities, including developmental delays, and the importance of early intervention.



Insufficient special education services

- Caregivers noted a lack of access to special education services due to limited knowledge of where to go and who to see to access those services.

2020 Needs Assessment: CYSHCN Health

- Special education services and integration of their children into school-based settings are unsatisfactory due to limited resources for special education services.
- Teachers and administrators may have limited knowledge of specific special health care needs and diagnoses.



Youth with SHCN are not meeting guidelines for physical activity and nutrition

- Youth with SHCN reported very limited regular physical activity.
- They also reported primarily sedentary activities, including:
 - o watching television
 - o listening to music
 - o spending time on their computer, tablet, or smartphone



Lack of provider workforce that is knowledgeable about CYSHCN, especially in rural areas and for adult services

- Across the state, few providers are knowledgeable about treating CYSHCN.

- Providers and services for CYSHCN are perceived as lower quality in rural areas.
- Caregivers want their children to receive high quality services and supports, but coverage limitations and high out-of-pocket costs often make it difficult or impossible to do so.
- Many providers do not accept Medicaid.



Lack of or inadequate accessibility and accommodation supports, including physical environment, interpreter services, and materials

- Caregivers expressed a lack of inclusion with typically developing peers and desired for their CYSHCN to be a thriving member of the community.
- There are limited recreational and extracurricular activities available for CYSHCN.
- Barriers to these activities include:
 - o limited knowledge of available community programs
 - o high cost of programs and services
 - o limited knowledge of community program providers on CYSHCN

- Community accommodations for CYSHCN with physical disabilities are limited, including a lack of adequate equipment at clinics for people with disabilities.
- Interpretation and translation services are limited when taking their child to health care appointments.



Lack of or inadequate access to timely assessments and appropriate referral

- There is a lack of early identification of developmental delays, due in part to limited provider and parent education and awareness of the importance of early identification.
- Availability of and access to screening and treatment centers is limited. There is a backlog of screenings and long wait lists at screening centers.
- Caregivers encounter the following barriers to receiving assessments and referrals:
 - o Insurance does not cover service or provider
 - o Out-of-pocket cost is too high
 - o Long wait list
 - o Providers are unwilling to screen

What We Know: Federally Available Data

CYSHCN Indicators	Value*	How does Mississippi compare to the U.S.?	How has Mississippi been doing?
Medical home	46.9%	Better	Trending better
Transition**	22.3%	Slightly better	Trending slightly worse
Adequate insurance	68.1%	Better	Trending slightly better
CSHCN 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)	15.6%	About the same	No change
Mental health treatment	Data not available specifically for CYSHCN at state level.		
Forgone health care			
Child vaccination			
Flu vaccination			
HPV vaccination			

* Data values are most-recently available as retrieved from <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures> and <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures> and *National Survey of Children's Health: childhealthdata.org*

**Data may be unreliable due to small sample



Source: <https://www.childhealthdata.org/browse/survey>