

State of State Title V SFY26 – Bureau of Family Health – Office of Public Health

Title V Programs, funded through the federal Maternal and Child Health Services Block Grant, play a vital role in supporting individuals with disabilities, especially children and youth with special health care needs (CYSHCN), and their families. Authorized under Title V of the Social Security Act, these programs operate in every U.S. state and territory. In Louisiana, the Bureau of Family Health (BFH), housed within the Office of Public Health, administers the state’s Title V Program.

The National Survey of Children’s Health assesses the physical and emotional well-being of children ages 0–17. According to the 2022–2023 dataset, more than 257,000 children in Louisiana—representing 24% of the state’s pediatric population—qualify as having a special health care need (SHCN) based on the nationally recognized screener. When applying newly expanded criteria for SHCN status, this number rises to 339,651, or 32%. In addition, the survey identifies over 268,000 children ages 3–17 with a mental, emotional, developmental, or behavioral (MEDB) concern. These challenges are further compounded by Louisiana’s ranking as second in the nation for children ages 0–17 living in poverty. Collectively, these data highlight a pediatric population at significant risk for poor long-term health outcomes.

Title V programs that directly support children SHCN and disabilities:

- Children’s Special Healthcare Services (CSHS)
 - Provides pediatric sub-specialty clinics for children and youth with special health care needs in Louisiana Department of Health Regions public health units to meet the specialty care needs in provider shortage areas.
 - Offers transportation assistance for medical appointments to eligible families through the CSHS transportation program.
- Early Hearing Detection and Intervention Program ensures:
 - All babies born in Louisiana have:
 - Received a hearing screening by 1 month of age (98% of LA babies, national benchmark 95%),
 - All babies who need additional testing after inpatient/outpatient screening are:
 - Diagnosed by 3 months of age (71% of LA babies, national benchmark 85%),
 - All babies who are identified as deaf or hard of hearing are:
 - Enrolled in early intervention by 6 months of age, supporting optimal language, literacy, cognitive, and social-emotional development (54% of identified LA babies, national benchmark 80%), and
 - Enrolled in family-to-family support (50.5% of identified LA babies)
- Family Resource Center (FRC)
 - A statewide center supporting families of children with special health care needs.
 - Collaborates with the Louisiana Birth Defects Monitoring Network (LBDMN) to provide information, services, and resources.
 - Currently expanding its impact through the Extreme Premie Project and new efforts to engage military families through targeted referrals.
 - Receives referrals from BFH community-based partners, providers, and directly from families. Over sfy25 outreached to 1136 and engaged 775 families.
- Genetic Diseases Program
 - Operates a comprehensive newborn heel stick screening (NBS) program that meets national standards and ensures access to follow-up genetic services.

- Manages the Sickle Cell Disease (SCD) Program, offering information and referral pathways to SCD foundations and clinics across Louisiana.
- State-run genetics clinics provide genetic evaluation, counseling, education, treatment, and referrals for individuals at risk of or diagnosed with genetic disorders.
- Louisiana Birth Defects Monitoring Network
 - Tracks more than 70 structural, functional, and genetic birth defects through active statewide surveillance.
 - Identifies potential environmental exposures, pharmaceutical risks, or behavioral contributors to birth defects in children diagnosed before their third birthday.
 - Current birth defects prevalence in Louisiana is 2.75% per 10,000 live births.
- Louisiana Commission for the Deaf
 - Provides individuals who are d/Deaf, DeafBlind, or hard of hearing with programs, services, and resources to ensure full access to communication and community engagement.
- Medical Home Initiative/Technical Assistance Center (TAC)
 - Promotes the pediatric medical home model—a family-centered, team-based approach to comprehensive, coordinated primary care, considered the gold standard for pediatric care.
 - Offers no-cost training and implementation support to Louisiana providers to expand their capacity to deliver high-quality, efficient medical home care.
 - In SFY26, the Medical Home TAC will further evolve into a streamlined hub for training, technical assistance, and resource dissemination for providers serving CYSHCN across the state.

Families as well as health providers consistently report challenges with navigating the early childhood system of care in our state.

Potential collaborative opportunities between Title V and Developmental Disability Council include co-sponsoring and coordinating promotion of family and health provider education that deliver information on key topics related to the care of and services for children with SHCN and disabilities. Promoting the pediatric medical home as the standard of care for health care delivery in the state. Messaging the importance of early hearing screenings and the key screening, diagnostic, and treatment milestones to ensure children who are deaf or hard of hearing receive appropriate and timely intervention options. Supporting cross agency collaborations around the care and wellbeing of the pediatric population in the state.