

Office of Public Health (OPH) Quarterly Report to the DD Council
Bureau of Family Health (BFH)
March 26, 2019

Children and Youth with Special Health Care Needs (CYSHCN) Programs

Children's Special Health Services (CSHS) works to ensure that CYSHCN in Louisiana have access to health care services designed to minimize their disabilities and maximize their probabilities of enjoying independent and self-sufficient lives.

- CSHS currently provides direct service clinics for CYSHCNs in regions 2 and 4-9 to meet specialty care needs in provider shortage areas. CSHS clinics are staffed by part-time physician sub-specialist, a full-time nurse, and parent liaison. CSHS parent liaisons are the parent of a child/young adult with a special health care need and work in tandem with the clinic staff to assist parents with coordination of care and linkage to community services. In Regions 2, and 6-9, the care team also includes a social worker.
- CSHS supports care coordination (CC) services in six academic clinics through partnerships with Children's Hospital New Orleans (CHNOLA), Daughters of Charity, NOELA Community Health Center, Lafayette General Hospital - University Hospital and Clinics, and Tulane Lakeside Pediatrics clinic. This project provides area families access to CC services and allows residents to gain personal experience with the medical home delivery model.
- CSHS promotes comprehensive developmental screening (DS) in pediatric primary care practices around the state. Providers who serve the birth to five population can participate in free technical assistance (TA) for DS and CC. Details on this TA opportunity are located online at <https://partnersforfamilyhealth.org/developmentalscreening>.
- Serving in the role as the Learn the Signs. Act Early. (LTSAE) Ambassador to Louisiana, the DS Coordinator has piloted LTSAE trainings with two of the state's Maternal, Infant, and Early Childhood Home Visiting (MIECHV) teams in Northern Louisiana, and the materials will be integrated into home visiting teams statewide after the MIECHV Annual Education Event in April. The materials have been integrated into the DS TA package administered to partnering primary care providers. To learn more about the LTSAE program and materials, visit the website <https://www.cdc.gov/ncbddd/actearly/index.html>
- CSHS hosted a Resource Information Workshop (RIW) *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs* on March 28, 2018 at University Medical Center in New Orleans Louisiana.

The CSHS Family Resource Center (FRC) located on the campus of Children's Hospital in New Orleans, connects Louisiana families with needed resources through outpatient clinics and the inpatient rehabilitation unit. The FRC also links families with their local Families Helping Families center for ongoing support.

FRC staff continue to attend Botox, Spasticity, Neuromuscular, Spina Bifida, Down Syndrome, Muscular Dystrophy, Cerebral Palsy and Neurology Transition clinic. The FRC youth liaison also visits families receiving inpatient rehab services and provides information about the resource center. Additional FRC activities:

- FRC parent liaison, Thuy Nguyen, serves on the CHNOLA Commission on Accreditation of Rehabilitation Facilities (CARF) providing the family perspective and resource information to inform the group’s work.
- FRC youth liaison, Steven Nguyen, participates in the Statewide Independent Living Council and serves in the role of vice chairman; sits on the Developmental Disabilities Council; and is a member of the Jefferson Parish Complete Streets Coalition.
- FRC staff hosted an information table at the CHNOLA Rehab Reunion.

Family Resource Center	
Resource Dissemination Activities December 2018-February 2019	
Total Client Encounters	130
Identified Resource Needs	343
Resource Needs Met	321

Louisiana Birth Defects Monitoring Network (LBDMN) tracks the occurrence of over 70 structural, functional, and genetic birth defects in Louisiana residents. This work helps to identify environmental conditions, pharmaceutical side effects, or behavioral risk factors threatening Louisiana's newborns.

- LBDMN contributed data to the MMWR manuscript examining Gastroschisis Trends and Ecological Trends to Opioid Prescription Rates in the United States published in Volume 68, No. 2 on January 18, 2019. See pages 31-36 at <https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6802-H.pdf> . The manuscript received media attention from HealthDay, Washington Post AP, CNN online, and a perspectives piece in the AAP’s Pediatrics Perspectives entitled “Public Health Surveillance of Prenatal Opioid Exposure in Mothers and Infants”. <http://pediatrics.aappublications.org/content/pediatrics/early/2019/01/15/peds.2018-3801.full.pdf> .
- LBDMN partnered with the LA HIV program to contribute to the CDC surveillance-linking project for preliminary matching of 2013-2017 occurrences of neural tube defects and maternal HIV exposure. The purpose of the project was to determine necessity of further investigation to assess risks of neural tube defects after periconception exposure to dolutegravir (DTG), an antiretroviral used in HIV therapy. The draft of the project has been approved. It is expected to be released in the MMWR in the near future.

CSHS Transportation Assistance Program provides needed transportation assistance for families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS and meet CSHS transportation program eligibility.

Transportation Assistance Program December 2018-February 2019	
42 families served	Stipend expenditures \$5,903.81

Hearing Speech and Vision - Early Hearing Detection and Intervention (EHDI) Program is a national initiative that supports the early identification of infants who are deaf or hard of hearing (D/HH). The goals of the program are to complete screening before 1 month of age, complete audiologic evaluation before 3 months of age, and enrollment in early intervention before 6 months of age. The program works to ensure all children who are deaf or hard of hearing can effectively communicate and develop the language skills they need to learn, grow and thrive.

- Act 455 of 2018 established a Language Equality and Acquisition for Deaf Kids, LEAD-K, task force. The Task Force consisted of twenty-three members jointly appointed by the Secretary of the Department of Health and the State Superintendent of Education to develop a framework for assessing children who are deaf or hard of hearing to determine language skills and ensure kindergarten readiness. The LEAD- K task force convened six times between July 2018 - January 2019. Following deliberations, they included the following recommendations in their report to the Legislature on February 1, 2019. The task force recommended that Louisiana should use the SKI-HI Language Development Scale to assess the language milestones of students who are deaf or hard of hearing. They also recommended that Louisiana should produce a resource document that outlines tools available to measure language skills, requirements for administration of each tool, and the ability to be administered in spoken English and/or American Sign Language. The task force recommended that assessments should be completed and reported every six months to ensure ongoing monitoring of language development. With respect to data collection, the task force also recommended that the state's data system to support the monitoring of language acquisition include the following information: 1) date of identification, 2) person who made identification, 3) type, degree, and configuration of hearing loss, 4) basic demographic information (including history of deafness or hearing loss), 5) mode of communication and language used at home, 6) other diagnosis, 7) information dissemination to families, 8) child progress towards milestones, assessment results, 9) any technology used, 10) language of choice, and 11) mode of communication. Additionally, the task force recommended that the designated data system allow authorized providers to input assessment results and other necessary information. Finally, the task force recommended that the data system allow state agencies to analyze data to support identification of systemic trends.
- The LA AAP Chapter Champion, four EHDI staff, and one parent from GBYS attended the National EHDI Meeting in Chicago March 2-6th. The meeting afforded unique opportunities to learn about national trends, challenges and successes of other states' EHDI programs as well as offering opportunities to

strengthen relationships and further collaborations made while networking in a continued effort to support the goals and mission of EHDI programs nationwide.

Louisiana Guide By Your Side (GBYS) is the lead family based organization for the LA EHDI program. GBYS is a program from Hands and Voices (H&V) that provides support and unbiased information from trained Parent Guides to families of newly identified children who are deaf or hard of hearing.

- Parent Guides host a variety of parent networking activities across the State to connect families with one another and to provide education about local supports and services including the new Deaf and Hard of Hearing Guides recently added to the GBYS program.
- In March, Guides hosted Coffee Chats in various regions across the State where they provided IFSP and IEP training to families in attendance.

Genetic Diseases Program operates a comprehensive statewide newborn heel stick screening program meeting national standards as well as ensuring access to genetic evaluation and counseling to residents of Louisiana. The Genetics Program also operates the Sickle Cell Disease (SCD) Program, which provides resources and information on how individuals diagnosed with sickle cell can receive assistance and care through the Sickle Cell Foundations and Clinics around the state.

- Since the addition of Severe Combined Immunodeficiency (SCID) to Louisiana Newborn Heel Stick Screening Panel, the Genetic Diseases Program has been working in conjunction with the Jeffrey Model Center to educate pediatricians and parents about this inherited condition. The Genetics Staff developed educational resources on SCID that are being distributed throughout the state.
- The Genetics Program has been collaborating with LDH IT and DBSysgraph to integrate a Genetics Module in the Louisiana Electronic Event Registry System (LEERS). The Genetic Module will allow birth records clerks to enter newborn screening data to improve the speed of reporting abnormal results and tracking of infants. The Genetics Program has implemented a pilot study with Ochsner Medical Center- West Bank to test the new module.
- Global Blood Therapeutics, Inc. presented on their new clinical therapies for sickle cell disease at the Louisiana Sickle Cell Commission Quarterly Meeting in December 2018. Attendees of the meeting included representatives from the Sickle Cell Clinics, Sickle Cell Community-Based Foundations, Healthy Louisiana Medicaid Managed Care Organizations, and the Louisiana Department of Health.
- Hematologists and Medical Students at the Ochsner Health Center for Children are collaborating with the Genetics Program on a research project. The project will research the percentage of children with sickle cell disease who received the CDC recommended vaccinations compared to children without high-risk conditions.

Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program (LHHCLPPP) works toward the goal of eliminating childhood lead poisoning as a public

health problem through initiatives to promote lead poisoning prevention and coordinate lead abatement projects for low-income families in high-risk areas of the state.

1. Lead Program delivered two presentations at the 2019 American Maternal and Child Health Program (AMCHP) Annual Conference. As participants in the Maternal Child Environmental Health Collaborative Improvement and Innovation Network (CoIIN) sponsored by AMCHP, the Lead Program was invited by AMCHP to present our findings in two presentations at the Annual AMCHP Conference. The two sessions presented:
 - Strengthening Quality Improvement and Innovation through Family Engagement in Collaborative Improvement and Innovation Networks
 - Environmental Health Partnerships to Reduce Child and Maternal Lead Poisoning in Communities Across the US

2. Lead Testing Project with Crescent City WIC Program Update:
 - **Success of this Initiative:** the team exceeded the project goal to test 125 children between September and January (25 children lead tested per month). The program reached 263 children, doubling the goal!

BFH Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program is a no-cost, voluntary program that supports the health and well-being of families with young children. MIECHV implements two evidence-based models, Nurse-Family Partnership (NFP) and Parents as Teachers (PAT). MIECHV pairs families looking for additional support and mentoring with specially trained registered nurses or parent educators who partner with families.

NFP and PAT services:

- Health and developmental screenings for children, promoting early identification of developmental delays.
- Assistance with goal setting and life skills development.
- Parenting guidance on a variety of topics.
- Connections to available resources, including early intervention and early childhood special education services.
- Coordinated care and support once families are connected to needed services.

Maternal, Infant, and Early Childhood Home Visiting Program SFY 2018 Reach		
Nurse Family Partnership	3,108 families served	31,530 home visits
Parents as Teachers	709 families served	7,487 home visits

For more information about Louisiana MIECHV's NFP and PAT services, including how to get in touch with a home visitor near you, please call the Partners for Family Health toll free telephone line at 1.800.251.BABY or visit the Partners for Family Health website at <https://partnersforfamilyhealth.org>.