

**Office of Public Health (OPH) Quarterly Report to the DD Council
Bureau of Family Health (BFH)
September 26, 2018**

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

Children's Special Health Services (CSHS) works to ensure that children and youth who have special health care needs 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 continues 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 can be located at <https://partnersforfamilyhealth.org/developmentalscreening>. Through a partnership with the Louisiana AAP Chapter, links to the DS materials are now available on LA AAP's new ADHD Toolkit website! Site access and use of ADHD tools is free. Providers can access the toolkit at <http://www.laaap.org/adhd-reg/>
- Serving in the role as the *Learn the Signs. Act Early.* (LTSAE) Ambassador to Louisiana, the DS Coordinator has created and scheduled developmental monitoring trainings to pilot with two of the state's Maternal, Infant, and Early Childhood Home Visiting (MIECHV) teams in Northern Louisiana. 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 at <https://www.cdc.gov/ncbddd/actearly/index.html>
- CSHS will host a Resource Information Workshop (RIW) on Thursday, September 27, 2018 at the Lake Charles Civic Center. The RIW *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs* (CYSHCN), includes 4 hours of continuing education for nurses, social workers, and Licensed Professional Counselors. Continuing Education topics address Care Coordination, Youth Health Transition, Developmental Screening and Community Supports and Services.

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.

This quarter, FRC staff attended 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. A new Skeletal Dysplasia clinic is slated to begin late 2018.

Additional FRC activities:

- August presentation to the CHNOLA Family Advisory Council around available FRC services.
- July meeting with Exceptional Lives Louisiana Team to facilitate ongoing collaboration.
- 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.

Family Resource Center Resource Dissemination Activities June-August 2018	
Total Client Encounters	194
Identified Resource Needs	342
Resource Needs Met	367

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.

Louisiana Environmental Public Health Tracking Network has uploaded our 2007-2011 birth defects data to the Louisiana Department of Health's online data exploration tool, the Health Data Portal at <http://healthdata.dhh.la.gov/>. The 2012-2014 birth defects data was submitted for the next portal update. Louisiana residents and the public can now access data ranging from birth defects to colorectal cancer at the parish-level (rates and counts) and other health data on the portal. A searchable glossary, zoomable maps and "pop-out" display windows that expand are just a few of the new features that have been added to enhance the end user's experience.

Traditional Case Definition Surveillance:

- The 2014 birth cohort closed at the end of December 2017. Analysis is pending. The 2015 birth cohort is targeted for completion at the end of October 2018. Note: birth cohorts are closed within 3.5 years due to our case definition of following children up to their third birthday.

Zika Case Definition Surveillance:

- The CDC grant cycle for surveillance of birth defects related to Congenital Zika virus exposure closed 7/31/2018.
- LBDMN submitted approximately 256 cases of interest from among 2016- 6/30/2017 births with birth defects associated with perinatal Zika exposure to help establish prevalence rates of these birth defects among exposed and non-exposed populations.
- 49 of 51 birthing hospitals in the state partnered with LBDMN to submit revised discharge reports with the Zika codes for 2016-17 discharges. The remaining hospitals did allow remote abstractions of cases identified through supplemental data sets.
- Among the 51 reporting facilities, remote access was secured for record abstraction at 35 sites.
- It is noteworthy that Louisiana has ***not had any live births*** with maternal Zika exposure or Congenital Zika Syndrome to follow for referral, care coordination, health or developmental outcomes.

New Projects - LBDMN has had the opportunity to contribute to two CDC specialized data calls recently:

- In July, we contributed data to investigate the relationship between occurrences of gastroschisis and opioid prescription rates in the United States for the birth years 2006 – 2016.
- Currently, we are gathering neural tube defect data for preliminary matching of 2013-2017 birth defects and HIV data to determine necessity of further investigation to assess risks of neural tube defects after periconception exposure to the antiretroviral Dolutegravir (DTG) medication. LBDMN is collaborating with OPH HIV surveillance partners for this special interest CDC project. CDC is especially interested in partnering with Louisiana because of the high quality of data in both of our programs and our ability to collaborate administratively within OPH.

CSHS Transportation Assistance Program provides needed transportation assistance for families to attend medical appointments/procedures.

Travel stipends are funded at \$60,000 per fiscal year and were suspended in April 2018 due to a depletion of funds. Program supports resumed as of September 17, 2018.

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. Currently the heel stick program screens for 28 genetic conditions. 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.

- The Louisiana Office of Public Health, through its Genetic Diseases Program, received the official Notice of Grant Award as a recipient for the Human Resources and Services Administration (HRSA) Newborn Screening State Evaluation Program. The purpose of this program is to evaluate the effectiveness of newborn screening programs in reducing the morbidity and mortality caused by heritable disorders in newborns and children, by

assessing the timeliness of screening, follow up, and referral to counseling or health care services. This will be accomplished by supporting state newborn screening programs in the implementation of a demonstration program to use newborn screening quality indicator information to evaluate the effectiveness of their state newborn screening system.

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.

- The LHHCLPPP received notice of the 3 year CDC Lead Poisoning Prevention Grant.
- The team also received a Maternal and Child Environmental Health (MCEH) COIN Grant and the team attended a national training conference in Washington, DC at the end of July.
- MCEH grant activities include a collaboration with the Crescent City WIC office and Orleans Parish Head Start Centers promoting an increase in lead testing of children.
- The Lead team would like to congratulate Dr. Trina Evans Williams and Jonathan Whipple who are now Certified Lead Inspectors and Certified Risk Assessors.
- The program is currently finalizing plans for activities to celebrate the Annual Lead Poisoning Prevention Week October 21st- 27th, 2018!

Hearing Speech and Vision - Early Hearing Detection and Intervention (EHDI) Program

EHDI 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.

- EHDI staff attended the LA Academy of Audiology Conference to obtain feedback from LA EHDI database (LA EHDI-IS) users, and to enroll new users in the electronic reporting system (LA EHDI-IS)
- The EHDI program co-hosted the CONNECTIONS Conference at LSU-HSC New Orleans, in collaboration with the Deaf/Blind Project on September 13-14. Conference topics included information on mild and unilateral hearing loss and a presentation on the Theory of Mind.
- Quarterly learning community meetings continued to engage health care professionals and families to improve the coordinated care provided to deaf or hard of hearing children and their families.
- The EHDI Program AAP Chapter Champion is attending the National Congenital Cytomegalovirus (CMV) Conference. The goal of the conference is to present the latest research on diagnosis and treatment, delineate prevention efforts, provide information on early intervention options, and disseminate family support resources.
- The Early Identification of Deaf or Hard of Hearing Infants Advisory Council is revising the parent copy of the Newborn Hearing screening report form to provide a positive message to all families of infants who have been screened.

Louisiana Guide By Your Side (GBYS) is the lead family 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.

- The GBYS Program Manager and the Bilingual Parent Guide attended the National Hands & Voices leadership conference in Cheyenne, Wyoming.
- Hands and Voices is in the process of hiring and training Deaf and Hard of Hearing Guides and initiating a Deaf Mentoring program.

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 and provide personal home visits.

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.

Nurse Family Partnership (NFP):

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible first-time moms and families from pregnancy until the child's second birthday.
- NFP serves moms living in all parishes except Caldwell, East Carroll, Madison, Tensas, Union, and West Carroll.

Parents as Teachers (PAT):

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible expectant or parenting families from pregnancy until the child enters kindergarten.
- PAT serves families living in Northern Louisiana and the New Orleans area.

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>.