

**Office of Public Health (OPH) Quarterly Report to the DD Council**  
**Bureau of Family Health (BFH)**  
**December 12, 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 are located online at <https://partnersforfamilyhealth.org/developmentalscreening>. Through a partnership with the Louisiana AAP Chapter, links to the DS materials are available on LA AAP's ADHD Toolkit website! Toolkit use is free and can be accessed 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 hosted a Resource Information Workshop (RIW) on September 27, 2018 in Lake Charles Louisiana. The *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs (CYSHCN)* workshop hosted 22 nurses, 14 social workers, 5 Licensed Professional Counselors, and 21 general audience attendees. Provider education topics included Care Coordination, Youth Health Transition, Developmental Screening and Community Referrals for CYSHCN.

**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.

Additional FRC activities:

- Met with Our Lady of the Lake representatives around a planned resource center to support the new children’s complex.
- 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 parent and youth liaison staff attended a November 29<sup>th</sup> training on youth health transition.

<b>Family Resource Center</b>	
Resource Dissemination Activities September-November 2018	
Total Client Encounters	177
Identified Resource Needs	500
Resource Needs Met	486

**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.

The January 2019 National Birth Defects Prevention Month toolkit is now available at <https://www.nbdpn.org/bdpm.php> (entire toolkit can be downloaded at [http://www.nbdpn.org/docs/2019\\_BDPM\\_Packet\\_FINAL.pdf](http://www.nbdpn.org/docs/2019_BDPM_Packet_FINAL.pdf)).

*The theme is ““Best for You. Best for Baby. 5 Tips for Preventing Birth Defects.”*

*Tip 1: Be sure to take 400 micrograms (mcg) of folic acid every day.*

*Tip 2: Book a visit with your healthcare provider before stopping or starting any medicine.*

*Tip 3: Become up-to-date with all vaccines, including the flu shot.*

*Tip 4: Before you get pregnant, try to reach a healthy weight.*

*Tip 5: Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs.*

This toolkit was developed in collaboration with many partners, including the Centers for Disease Control and Prevention (CDC), American Academy of Pediatrics (AAP), Teratology Society, MotherToBaby, March of Dimes, and state birth defects programs. This first page of the toolkit includes a synopsis of suggested audience, how to use the toolkit content, a list of available resources, and social media suggestions. Please use the hashtag #Best4YouBest4Baby on Facebook, Twitter, Instagram, and other channels to help us track engagement.

We invite you to tailor the resources and share with colleagues, policy makers, families, and others during National Birth Defects Prevention Month in January 2019 and throughout the year.

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

CSHS worked with Families Helping Families at the Crossroads, Medicaid, and the BFH Strategy Manager to outline a protocol to ensure families seek transportation assistance through their MCO before requesting assistance through CSHS. This protocol includes contact information for each MCO and a special emphasis on criteria for granting CSHS assistance. Travel stipend parameters were updated for lodging, meals, and mileage reimbursement.

<b>Transportation Assistance Program</b>	
October 2018	
19 families served	Stipend expenditures \$2,726.08

**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.

- Severe Combined Immunodeficiency (SCID) will be added to Louisiana Newborn Heel Stick Screening Panel effective December 10, 2018.
- SCID is an inherited condition in which the body is unable to fight off serious and life-threatening infections.
- The Genetics Staff attended the 7th Jeffrey Modell Center- Louisiana Primary Immunodeficiency Network Symposium on November 30 and December 1 in New Orleans sponsored by LSU Health Sciences Center New Orleans and Children’s Hospital.
- The focus of the symposium was Newborn Screening in Louisiana: The Impact of Early Diagnosis and Treatment of Primary Immunodeficiency.
- Dr. Daniel Ferguson, Director OPH Laboratory Services, presented on the implementation of newborn screening for SCID in Louisiana.

**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 team's Maternal and Child Environmental Health (MCEH) COIIN 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 Crescent City WIC office exceeded their quarterly goal of testing 100 children for lead by testing 188 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.

### **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.

LDH and DOE have been partnering since August with a Task Force dedicated to the Language Equality and Acquisition for Deaf Kids (LEAD K) initiative. This initiative is aimed at improving language and literacy outcomes for children who are Deaf and Hard of Hearing with an emphasis on Kindergarten readiness.

The LA AAP Chapter Champion and the LA EHDI Program Manager attended the CMV (Cytomegalovirus) Public Health & Policy Conference. A Louisiana CMV Awareness Committee will be formed to determine next steps for CMV awareness. .

The EHDI Program has reduced the number of infants who become lost to follow-up after receiving a further testing needed result from their initial newborn hearing screening. In 2016, 22.1% babies were lost to follow-up, and in 2017, 17.6% of babies were lost to follow-up, which is an overall reduction of 20.7% in the lost to follow-up rate.

**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.

To initiate the addition of D/HH guides to the LA Chapter of the H&V GBYS program, the LA EHDI program held a two-day training in October 2018. National H&V trainers conducted the training for potential deaf and hard of hearing guides, as well as the current H&V GBYS parent guides. Following the training, four new D/HH Guides were hired to work alongside the GBYS Parent Guides.

**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

pecially 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.

<b>Maternal, Infant, and Early Childhood Home Visiting Program SFY 2018 Reach</b>		
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>.