

Office of Public Health (OPH) Quarterly Report to the DD Council
Bureau of Family Health (BFH)
June 27, 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 6 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) around comprehensive DS and CC. Details on this TA opportunity can be found at <https://partnersforfamilyhealth.org/developmentalscreening>.
- The CSHS DS Coordinator was selected by the CDC Act Early Project to serve as the Act Early Ambassador to Louisiana. The Learn the Signs. Act Early (LTSAE) ambassador project consists of a network of representatives across the country that promote family engagement in developmental monitoring using the LTSAE materials. The ambassador's work plan includes implementation of the LTSAE materials in pediatric primary care via the DS TA initiative, as well as through the state's Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program. 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 Thursday, April 26, 2018 at the North Oaks Diagnostic Center in the E. Brent Dufreche Conference Center. The RIW *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs (CYSHCN)*, offered 4 hours of continuing education credit for nurses, social workers, and Licensed Professional Counselors. Continuing Education topics included Care Coordination, Youth Health Transition, Developmental Screening and Community Supports and Services. Event attendee breakdown: Social workers-65, LPCs-4, Nurses-21, General-15, Vendors-16.

The CSHS Family Resource Center (FRC) located on the campus of Children’s Hospital New Orleans, LA 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 the Botox, Neuromuscular, Spina Bifida, Down Syndrome, Muscular Dystrophy, Cerebral Palsy and Neurology Transition clinic. The launch of the Skeletal Dysplasia clinic was pushed back. The FRC youth liaison also visits families receiving inpatient rehab services and provides information about the resource center.

- The 2018 FRC Resource fair at CHNOLA on *Early Childhood Behavioral Health* was a great success, with 22 agencies participating and 79 healthcare providers attending.
- The 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.
- The 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 March-May 2018	
Total Client Encounters	207
Identified Resource Needs	453
Resource Needs Met	430

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 next update including 2012-2014 birth defects data will begin in August. 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 completion is targeted for 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 closes 7/31/2018.

- Abstraction continues for 2016-17 potential cases of interest for Zika related birth defects.
- All but two (49 of 51) birthing hospitals in the state have submitted revised reports with the Zika codes for 2016-17 discharges.
- We have secured remote access for record abstraction at 35 of 51 reporting facilities that have remote capability and are willing to grant permissions to outside entities.
- 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.

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

Transportation Assistance Program February – April 2018	
86 families served	Stipend expenditures \$9,445.77

Travel stipends are funded at \$60,000 per fiscal year. Stipends were suspended in April 2018 due to a depletion of funds.

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 LDH Genetic Diseases Program, in partnership with Ochsner Medical Center and the Louisiana Sickle Cell Commission, hosted the 2018 Sickle Cell Statewide Conference on June 8-9 at the Ochsner Medical Center Campus in New Orleans. Parham Jaberi, MD, MPH, Assistant State Health Officer, attended the conference and inaugurated the symposium on behalf of the Department of Health. The two-day summit increased awareness and enhanced the knowledge of the community about SCD. Medical and social service providers received CEUs while hearing subject matter experts on topics including the role of the healthcare professional, pain management, advocacy, youth health transition, bone marrow transplant, and support services. In addition, the conference highlighted clinical trials, held an interactive panel discussion. Approximately 90 individuals living with sickle cell, family members, community advocates, physicians, nurses, mental health providers and healthcare providers attended the seminars and received resources. Exhibitors included the Healthy Louisiana Plans and pharmaceutical companies.
- The Partners for Healthy Babies social media accounts displayed information to increase public knowledge and raise awareness of SCD and the struggles experienced by individuals and their families in accord with World Sickle Cell Awareness Day, June 19th.

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 program celebrated Louisiana Healthy Home Month during June with a robust calendar of events.

Louisiana Healthy Home Month activities included:

- Free lead testing at WIC clinics in the parishes of Orleans, Jefferson, Plaquemines and St. Bernard;
- Collaborations with American Academy of Pediatrics, WIC Providers, BFH programs to distribute the Lead Abatement Flyer;
- Promoted childhood lead poisoning prevention within the Maternal Infants and Early Childhood Home Visiting (MIECHV) Program and the Safe Sleep Campaign;
- Educated public health students, nursing students, and medical residents on the importance of healthy homes and lead poisoning prevention;
- Worked with housing partners to promote the Lead Based Paint Hazard Control Grant activities in targeted parishes.
- Raised awareness about healthy homes and lead hazards and its effects on human health by participating in radio show interviews, presentations, neighborhood association meetings, fire department canvassing, lead trainings, and events at area WIC clinics, local Head Start programs, state agencies, and community-based organizations.

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

conducts the newborn hearing screening program in Louisiana (LA). EHDI is a national initiative that supports the early identification of infants with hearing loss through screening, audiologic evaluation, medical evaluation, enrollment in early intervention, and family to family support services. In 2017 the EDHI Program reduced the number of infants who become loss to follow-up after failed newborn hearing screening to 18.8% from 22.3% in 2016.

Upcoming EHDI activities:

- CONNECTIONS Conference at LSU-HSC New Orleans, in collaboration with the Deaf/Blind Project, scheduled for September 13-14. Conference topics include information on mild and unilateral hearing loss and a presentation on the *Theory of Mind*.
- Quarterly learning community meeting to engage health care professionals and families to improve the coordinated care provided to deaf or hard of hearing children and their families.

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

- Work continues with the National Technical Resource Center for Newborn Hearing Screening and Intervention to improve family engagement, partnership and leadership within the EHDI System.
- Hands and Voices leadership are participating in the HRSA - Family Leadership in Language and Learning Program.
- Hands and Voices continues to offer family activities including a family picnic, a day at the Children’s Museum and a Roller-Derby fundraiser.
- Hands and Voices is currently recruiting Parent Guides who are deaf or hard of hearing.

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 Shreveport, Monroe and the 18 surrounding parishes and families in Orleans, Jefferson, St Bernard and Plaquemines parishes.

Maternal, Infant, and Early Childhood Home Visiting Program SFY 2017 Reach		
Nurse Family Partnership	3,205 families served	33,349 home visits
Parents as Teachers	596 families served	6,112 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>.