

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
January 5, 2021

Children's Special Health Services (CSHS) works to ensure that children and youth with special health care needs (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.

- Children's Special Healthcare Services (CSHS) - Clinical Services offers direct care clinics for CYSHCNs in all regions, except 1 and 7, to meet specialty care needs in provider shortage areas. CSHS-Clinical Services (Genetics, Sickle Cell, and subspecialty clinics) transitioned to mostly telehealth appointments at the beginning of the COVID-19 pandemic. Decisions regarding in-person visits are now being made at the Regional level depending upon staffing capacity, the infection positivity rate, and the ability to provide services safely.
- CSHS-Clinical Services Social Workers continue to provide behavioral health assessments to determine if families are in need of outpatient behavioral health referrals, as well as providing support and resources.
- CSHS-Clinical Services also provides nutritional services in Regions 2 and 6 and hopes to expand to other Regions as the need dictates.
- Any family of a child/youth with a special health need that requires peer support, system navigation, or resource linkage is referred the Families Helping Families network in their respective region or the Family Resource Center. CSHS-Clinical services also refers to other community-based organizations as appropriate.

The Family Resource Center (FRC) transitioned to a statewide virtual center to ensure CYSHCN, their families, and health care providers have access to resource and referral services during the pandemic. The FRC offers community referrals, CV19 resources and program updates, health/education transition supports, and system navigation services for Louisiana CYSHCN/families and health care providers. FRC staff are available by **phone 504-896-1340** or **email BFH-FamilyResourceCenter@la.gov** between 8am-4pm Monday through Friday.

Family Resource Center Sept 2020-Nov 2020	
Total Client Encounters	92
Resource Needs Provided	140

Families Helping Families – BFH Project aims to build a coordinated and family-centric statewide CYSHCN resource and referral service system utilizing the FRC virtual Center and partnering with FHF. FHF networks are Louisiana's statewide parent-to-parent support organization serving individuals with disabilities. In July, BFH launched a new initiative with FHF to ensure all CYSHCN in Louisiana have access to peer support and resource/referral services

within their communities. As part of this collaboration, FHF networks are engaged with expansion of service models to include services for all CYSHCN, those with and without disabilities.

CSHS Transportation Assistance Program provides needed transportation assistance for eligible families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS. New information resource materials are in development to ensure providers/families are aware of this service.

Transportation Assistance Program	
Jul-Nov 2020	
7 families served	Stipend expenditures \$524.48

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. By case definition, we include children diagnosed prior to their third birthday.

- LBDMN access issues due to the state ransomware attack are resolved. Onsite abstractions limitations continue due to the rise in COVID cases. Despite two extraordinary challenges impeding our work during the past fiscal year, our data collection specialists abstracted and submitted a half percent more cases than last year. Any increase in productivity speaks to their dedication!
- LBDMN submitted our annual report to the legislature in June. Some data highlights include:
 - Since 2005, LBDMN has investigated potential birth defects among 28,347 children
 - Of 169,699 children born in Louisiana between 2014 and 2016, 5,202 were diagnosed with at least one birth defect, yielding an overall prevalence of 305.6 per 10,000 live births or 3.1% (US, 3.0%).
 - Among children with birth defects, cardiovascular system defects (about 48%) were the most common followed (in order of occurrence) by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, central nervous, gastrointestinal, eye, and ear/face/neck systems. Other birth defects contributed about 5%
 - Total Annual Federal Funding State Fiscal Year 2019: \$644,550 (Title V Maternal and Child Health (MCH) Block Grant)
 - https://www.partnersforfamilyhealth.org/wp-content/uploads/2019/08/2019_LBDMN_Legis_Report.pdf
- In December, the LBDMN team submitted an application for the CDC grant to Advancing Population-Based Surveillance of Birth Defects. The project focuses on strengthening

the capacity of birth defects surveillance programs to respond to emerging threats to mothers and babies as a key component of preparedness, identifying and addressing mechanisms contributing to health disparities, and improving health outcomes among affected populations.

Genetic Diseases Program operates a comprehensive statewide newborn heel stick screening (NBS) 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.

Genetics and NBS

- The Genetic Diseases Program Advisory Committee Meeting occurred on October 23. The advisory committee discussed the revised guidelines for the committee and members. The committee also discussed the next steps for Spinal Muscular Atrophy (SMA) addition to the Louisiana newborn screening panel. The discussion also included proposed revisions to the state newborn screening rule and the program's response to areas of the state impacted during the hurricane season.
- The 2021 advisory committee dates are scheduled for January 29, April 23, July 23, and October 24, 2021.

Sickle Cell

- The Louisiana Sickle Cell Commission Quarterly Meeting occurred on December 8. The commission discussed the impact of COVID-19 among the sickle cell disease population in the state, developing a new strategic plan, a statewide conference in 2021, and potential legislative proposals for the 2021 Regular Sessions, and the next election of commission officials.
- The 2021 quarterly meeting dates are reserved. The quarterly meeting dates are March 9, June 8, September 7, and December 7, 2021.

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.

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 are identified early and supported effectively in order to have the opportunities to develop the language skills they need to learn, grow and thrive.

- Cytomegalovirus (CMV) awareness page was added to the LA EHDI website. CMV, a common viral infection, is the leading non-genetic cause of childhood hearing loss. One

in 200 children are born with CMV, and 1 in 3 pregnant women who become infected with CMV will pass the virus on to their child. In addition to congenital deafness or progressive childhood hearing loss, CMV can also lead to vision loss, microcephaly, behavior issues, intellectual disability, seizures, and cerebral palsy. Approximately 400 children die of congenital CMV each year. Despite its prevalence and seriousness, awareness of CMV is poor. According to the National CMV Foundation, only 9% of women in the United States have heard of CMV. In acknowledging the need to increase awareness of CMV and educate pregnant women on how to prevent transmission of CMV to their babies, the CMV awareness page was created and added to the Louisiana Department of Health's *Partners for Healthy Babies* webpage. The target audience for this webpage is expectant mothers. This is a first step in raising awareness of CMV and its prevention, and will serve as a foundation for future awareness initiatives.

- Through support from the Data Team within BFH, EHDI was able to analyze and display geographically referenced information using data attached to unique locations. This process enabled us to visualize the impact of geographic location on babies who become lost to follow-up for rescreening and diagnostic testing. The maps also enabled us to visualize the impact of geographic location on access to hearing aids and cochlear implants for children who are diagnosed as deaf or hard of hearing (DHH). The geographic mapping will be used in Regional meetings with program partners and other stakeholders as we share identified barriers to achieving 1-3-6 goals and strategize ways to bolster support.
- Every family with a child diagnosed as DHH under 3 years of age is mailed a flyer, **"Your Baby has been Diagnosed as Deaf or Hard of Hearing-What Families Need to Know"**. This flyer provides families with important information and resources to render guidance in the days after their child is identified as DHH. To meet the needs of families with children late identified, we created a revised version of the flyer for children ages 3 years and up since the content of the original flyer was designed for infants and very young children. The language of the revised flyer reflects older children and also provides information about the child's local school district instead of Part C. An informational flyer specifically for families with a child newly diagnosed with a unilateral hearing loss will be developed to address the unique needs of these children. In the first quarter of 2021, we will survey families of children with unilateral hearing loss to obtain feedback on their unmet needs to ensure that the flyer focuses on their specific needs.
- 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. To foster family engagement, H&V recently revised their website. The H&V Program Managers were able to meet with a BFH Communications Specialist to gain pointers for maximizing virtual content and engaging virtual readers. Work has begun on the development of bios for GBYS Parent Guides and DHH Guides. These bios will be added to the H&V website upon completion.

- Virtual events for families of DHH children began in the summer of 2020. Monthly Parent Chats are scheduled Zoom meets where families can share their current needs or concerns, or gather to gain support from one another. Future Parent Chats will include guest speakers presenting on a variety of topics including *Educational Toys and Ways to Use Them* and *Audiology 101 for Parents of Children Who Are DHH*. The H&V team continues family outreach and education through quarterly newsletters.
- H&V consults with the HRSA Family Leadership in Language and Learning (FL3) Center for resources, technical assistance, and training to strengthen the capacity for family engagement and family support. One of their most shared resources for families in Louisiana is the “8 Reasons to Say Yes to Early Intervention for your Child who is Deaf/Hard of Hearing” handout.

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.

LA MIECHV transitioned services to the exclusive use of telehealth March 2020. This transition is in alignment with public health best practice and guidance from the NFP and PAT national

offices. Telehealth will continue to be implemented as long as necessary, to ensure the health and safety of staff and families. LA **MIECHV continues to accept referrals and enroll new clients** during this time. 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>.

The Statewide Young Child Wellness Collaborative (YCWC) is a cross-agency advisory council, the purpose of which is to provide leadership and informed recommendations to drive shared priority setting and strategic planning across the continuum of supports and services within Louisiana's Early Childhood System.

The YCWC serves as the State-Level Advisory Team for the MIECHV program, and formerly for the SAMHSA-funded Project LAUNCH grant. The YCWC includes representation from BFH, EarlySteps, the Office of Behavioral Health (OBH), Medicaid, the Louisiana Department of Education (LDOE), the Louisiana Department of Child and Family Services (DCFS), LSU Human Development Center, the Louisiana Partnership for Children and Families, the Louisiana Policy Institute for Children, and the Louisiana chapter of the American Academy of Pediatrics.

The council recently completed the process of updating the **Louisiana Developmental Screening Guidelines**, a voluntary set of screening guidelines for pediatric and family medicine providers that aligns with and builds on AAP recommendations and Louisiana EPSDT mandates. These guidelines are intended to inform pediatric providers of the domains, recommended tools, and periodicity for universal comprehensive developmental screening for children in Louisiana.

BFH Adolescent School Health Program (ASHP) has 60 ASHP-certified School-Based Health Centers (SBHCs) across the state. These health centers are located in public and charter schools and offer comprehensive, primary, and preventive physical and mental health services for students enrolled in the school that houses the SBHC and surrounding schools.

SBHCs worked closely with school administrators and their sponsoring agency to develop re-opening plans that would support each of the three possible instruction models. This collaboration between the school and the SBHC allowed the SBHC to assist the school in COVID mitigation, management of chronic conditions, and meeting the behavioral health and physical health needs of students.

The LDH Adolescent School Health Program website <https://ldh.la.gov/index.cfm/page/565>.