

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
 Bureau of Family Health (BFH)
 October 8, 2020

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.
- CSHS-Clinical Services parent liaisons shifted under the Families Helping Families Centers in the community to ensure families have access to peer support and resource linkage. Any family of a child/youth with a special health need that requires peer support, system navigation, or resource linkage should contact the FHF center in their respective region.
- Implementation training and support is available to pediatric/adolescent primary care providers for developmental screening, care coordination, and youth transition services.

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 June 2020-August 2020	
Total Client Encounters	156
Resource Needs Provided	146

Families Helping Families – BFH Project aims to build a coordinated and family-centric statewide CYSHCN resource and referral service system. Covid19 presented an unexpected

opportunity for BFH to examine and test new models for providing CYSHCN resource support services in our state. With interruptions to in-person services at the health unit clinics and the FRC at Children’s Hospital, the bureau strategically moved parent liaison staff to the community under their contracting agencies (Families Helping Families [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, these networks are actively working to expand services to 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.

Transportation Assistance Program	
April-June 2020	
21 families served	Stipend expenditures \$3,059.85

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

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 Louisiana Newborn Screening Advisory Committee Meeting occurred on July 24. The advisory committee discussed the next steps for the addition of Spinal Muscular Atrophy (SMA) to the Louisiana newborn screening panel. The Advisory Committee will discuss the addition of X-linked adrenoleukodystrophy (X-ALD), Mucopolysaccharidosis type I (MPS I), and Pompe Disease to the state newborn screening panel at the next meeting scheduled for October 23.
- The State Newborn Screening Follow-up Program responded quickly to Hurricane Laura's disaster to ensure all infants born within the affected areas received a timely and valid newborn screen. Staff contacted 27 birthing facilities in Regions 4 through 7 to make sure they could collect newborn screen samples and transport them to the appropriate laboratories. The program disseminated to providers and guidance

circulated through the Newborn Screening Results Portal website, the Louisiana Chapter of the American Academy of Pediatrics, and other OPH platforms. Also, staff coordinated with Vital Records to obtain the list of all newborns from the affected areas to ensure proper screening.

- September was National Newborn Screening Awareness Month.

Sickle Cell

- The Louisiana Sickle Cell Commission Quarterly Meeting occurred on July 29. The commission discussed the impact of COVID-19 among the sickle cell disease population in the state, clinical guidance for managing acute complications, and legislative changes widening access to treatment options with the inclusion of sickle cell disease as a chronic pain condition. The next commission quarterly meeting will occur on October 23.
- September was National Sickle Cell Awareness Month. The sickle cell clinics and community-based organizations rescheduled the health fairs and fundraisers for the Spring of 2021 due to the impact of COVID-19.

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.

- The EHDI program recently closed out a three year grant cycle with the Health, Resources and Services administration, (HRSA). One of the goals through that funding period was focused on improving the number of infants and newborns who receive a timely diagnosis per Joint Committee on Infant Hearing (JCIH) recommended practice guidelines. Data analysis revealed that the percentage of infants receiving a timely diagnosis increased from 60.4% in 2014 to 72.8% in 2019, a 20.5% increase. Incremental improvements were observed annually from 2014 to 2019 for this measure. Several activities have addressed improving the number of infants diagnosed by 3 months of age. To increase awareness among professionals, an educational materials toolkit was developed for providers working with expectant parents and families of young children. This toolkit was utilized by EHDI Program staff to present information at meetings and conferences across the state with the Maternal, Infant and Early

Childhood Home Visiting (MIECHV) Program, EarlySteps (Part C of IDEA) personnel, and providers. MIECHV program participants also received LA EHDI-Information System training to enable them to access newborn hearing screening and follow-up data for the children they serve. To increase awareness among parents, calls, texts, and letters are sent to families of infants in need of further hearing testing. In addition, faxes are sent to the primary care providers of infants in need of further hearing testing.

- An additional goal addressed in the same three year HRSA grant cycle was that of increasing by 25% from baseline the number of newborns and infants who receive timely referral to EI per JCIH recommended practice guidelines. The percentage of infants receiving a timely referral to EI in 2014 was 46%. Incremental increases were consistently seen throughout the project period resulting in 84% (72/86) of the 2019 birth cohort being referred to EI by 6 months of age, which is an 83% increase. The primary factor responsible for the improvement was the increase in the number of children receiving a timely diagnosis by 3 months of age. For the 2019 birth cohort, 83% (71/86) of children identified with a PHL were identified by 3 months of age, and 94% (81/86) were identified by 6 months of age. Activities which led to this improvement included an analysis of the individual case progression of infants who did not receive a diagnosis by 3 months of age, which revealed factors that may have attributed to the late diagnosis. In an effort to improve diagnosis by 3 months, collaborative efforts were initiated with audiologists, and the following strategies were implemented: 1) scheduling diagnostic ABR after one failed outpatient screen, 2) providing unsedated diagnostic ABRs, 3) scheduling a diagnostic ABR after failed NHS for NICU babies, 4) contacting families of babies in need of outpatient testing at 3 weeks of age, and 5) notifying audiologists of the 48 hour reporting requirement for children diagnosed as D/HH to ensure timely referral to EI as per the Individuals with Disabilities Education Act (IDEA).
- In addition to the goal of timely referral to EI, there was a goal to increase by 20 percent from baseline the number of newborns and infants identified to be deaf or hard of hearing enrolled in EI services within JCIH recommended practice guidelines. The percentage of children enrolled in EI by 6 months of age increased from 56% in 2014 to 67% in 2019, a 20% increase. Several activities were implemented throughout the project period to improve the number of children enrolled in EI by 6 months of age. Physicians play a key role in communicating with families about the importance of timely early intervention and next steps that are needed. To ensure that PCPs of infants who are identified as D/HH are knowledgeable about their patient's diagnosis and referrals that have been made, a packet of information was developed and is mailed to each PCP when their patient is identified as D/HH. The packet includes their patient's audiological report, a list of referrals that have been made, and a conversation guide along with resources for next steps. Also, in an effort to ensure a coordinated and comprehensive continuum of care in which families are active participants, a document entitled "What Families Need to Know" was developed, and is now mailed to each family when their child is identified as D/HH. This document includes information about

why it is important to act fast, understanding communication options, hearing devices, learning with your child, what's next, resources and contact information.

- The EHDI program recently began a new four year grant cycle with HRSA and looks to address the following goals within our program work over the course of the next four years; 1) increase by 10 percent from baseline, or achieve a minimum rate of 85 percent, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age, 2) increase by 15 percent from baseline, or achieve a minimum rate of 80 percent, the number of infants identified to be DHH that are enrolled in EI services no later than 6 months of age, 3) increase by 20 percent from baseline the number of families enrolled in family-to-family support services by no later than 6 months of age, and 4) increase by 10 percent the number of families enrolled in DHH adult-to-family support services by no later than 9 months of age.

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.

- The H&V GBYS program has been working to support families virtually during COVID 19. Parent Chat Night sessions offered through the Zoom platform have proven to be an effective way for families to connect with one another, offer support and answer questions that many families have as they navigate supporting a child who is D/HH.
- The National Hands and Voices Conference took place virtually on Sept. 19, 2020. Members from the Louisiana H&V Team participated in the conference and enjoyed a variety of topics from *Supporting Families without Bias*, to *Fostering Joy*, and *Standing in the Gap-Navigating the New Normal*. Information gleaned during this conference will be used in supporting families in Louisiana and navigating next steps for growth among the Louisiana H&V Chapter.

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 2019 Reach		
Nurse Family Partnership	3,248 families served	33,565 home visits
Parents as Teachers	763 families served	7,063 home visits

LA MIECHV transitioned services to the exclusive use of telehealth, effective March 23, 2020, with telehealth visits beginning on March 25. 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 will continue to accept referrals and enroll new clients** during this time.

As MIECHV transitioned to telehealth, the IECMH team reviewed all MIECHV caseloads to assist with identifying potential client needs as a result of COVID-19, as well as identify potential increase in mental health acuity. Throughout telehealth, the IECMH team has continued providing consultation, joint visits, and Child Parent Psychotherapy via phone and approved software platforms. In-services for MIECHV teams have continued on a monthly basis, with IECMHCS providing training during team meetings using approved platforms.

In addition to telehealth services, regional Outreach Specialists are conducting remote outreach activities. Outreach Specialists are working to maintain established community partner relationships, and to gather information on community resources. Outreach Specialists are ensuring community partners are aware that MIECHV is continuing to enroll and provide services during COVID-19. Additionally, Outreach Specialists are sharing information about community resources with local home visiting teams to connect MIECHV families with additional supportive services.

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 is beginning the process to update the **Louisiana Developmental Screening Guidelines** with a goal set for December 2020 to have an updated and affirmed set of guidelines for pediatric healthcare providers. 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 with collaboration from YCWC members is developing an updated version of the **Louisiana Early Childhood Risk and Reach Report** to be released early 2021. This report will include maps of parish-level data around key risk factors in 5 domains that adversely affect children's health and well-being, as well as the parish-level reach of 8 publicly-funded early childhood programs. This report is intended to be used by a diverse range of stakeholders at the state and local levels to inform policy-making and the allocation of critical resources to better support young children and their families in Louisiana. The 2016 version of the report can be accessed here: http://ldh.la.gov/assets/oph/Center-PHCH/Center-PH/maternal/RiskandReach_Report.pdf.

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.

The Governor's mandate to close schools in March 2020 due to COVID-19 resulted in the need for SBHCs to consider alternative service delivery methods. Many of the SBHCs were positioned to immediately provide medical and behavioral health services via telemedicine, the remaining SBHCs are currently in the process of implementing telemedicine services. Three SBHCs in Cameron and Calcasieu parishes are currently closed due to Hurricane Laura. The SBHCs in Calcasieu plan to reopen within the next month. In Cameron, plans are underway to provide temporary services via a mobile unit with the SBHC scheduled to reopen in January of 2021.

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. Currently, 55 of the 60 SBHCs are actively providing services in schools throughout the state.

The LDH Adolescent School Health Program website (<https://ldh.la.gov/index.cfm/page/565>) was recently updated. New features include: added information about the supporting role ASHP plays in the operation of ASHP-certified SBHCs, a link to the list of SBHC sites, and a link to a SBHC Frequently Asked Questions.