

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
June 29, 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.

- CSHS offers direct service clinics for CYSHCNs in regions 2 and 4-9 to meet specialty care needs in provider shortage areas. The **CYSHCN clinics** (CSHS, Genetics, and Sickle Cell) services transitioned to mostly telehealth appointments due to COVID19. Staff Social Workers continue behavioral health check-ins to determine if families are in need of support or resources.
- CSHS 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) 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. Trained staff offer family to family and youth transition support. As part of BFH's response to the COVID19 incident, the Family Resource Center transitioned to a **statewide virtual resource hub**. The Parent and Youth Liaisons that previously supported the FRC are working in the community with Families Helping Families of Greater New Orleans.

The FRC center virtual resource hub is available to support any family or pediatric/family medicine provider with family resources, updates on community programs, and system navigation. Contact the **Family Resource Center at 504-896-1340** between the hours of 8 am and 4 pm – Monday through Friday or via email at BFH-FamilyResourceCenter@la.gov .

Family Resource Center March – May 2020	
Total Client Encounters	228
Identified Resource Needs	225
Resource Needs Met	429

CSHS Transportation Assistance Program provides needed transportation assistance for families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS.

Transportation Assistance Program January – March 2020	
68 families served	Stipend expenditures \$11,411.95

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 abstraction limitations due to COVID are beginning to be lifted. 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)

Once the report is posted online, the link will be forwarded for your review in its entirety.

- Family Engagement: Julie Johnston, LBDMN program manager, also serves as Louisiana's Title V Family Representative. Julie is mom to Zac, a 26 year old with medical complexity and developmental issues. Julie has had the following opportunities to represent the CYSHCN family perspective at the system and/or program level:
 - Participated as a panelist in the June AAP CYSHCN Network Café discussion of Emergency Preparedness for CYSHCN with Title V Leaders and The National Network for Advancing Systems of Services for CYSHCN Network, Catalyst Center, Got Transition, National Resource Center for Patient/Family-Centered Medical Home.
 - Contributed content an infographic for COVID Preparedness for CYSHCN produced EMS for Children

Please share widely! <https://emscimprovement.center/domains/preparedness/covid-19-coronavirus/family-preparedness/>

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 was held on May 8. The advisory committee discussed legislative mandates, expansion of the newborn screening panel, and the current membership. Subject matter experts discussed early diagnosis and multiple clinical therapies available for infants identified with Spinal Muscular Atrophy (SMA). The advisory committee recommended the addition of the SMA to the Louisiana newborn screening panel.

Sickle Cell

- House Bill 591 was approved during the 2020 Legislative Session. The Bill proposed expanding the list of governor-appointed members and removing the requirement of hosting the meeting in Baton Rouge. State Legislators approved to expand the list of eight appointed members to thirteen appointed members. The total number of commission members increased to seventeen. The increase in additional appointed members will allow for the inclusion of other individuals and families living with sickle cell to increase community stakeholder participation. On June 11th, the Governor signed House Bill 591 and enrolled it as Act 280 (HB 591) of the 2020 Regular Legislative Session.

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.

- In an effort to ensure that all babies continue to be screened and receive necessary follow-up during the Covid-19 Pandemic, the EHDI coordinator has been in ongoing contact with each hospital newborn hearing screening program supervisor, as well as each audiology practice that provides outpatient testing. The Program Director and Program Coordinator also participate in weekly calls with other state EHDI programs to discuss effective follow up strategies that ensure families are getting needed support.
- The EHDI Team has also been working on refining data points for the purpose of geopmapping. This visual map will highlight any correlations between provider locations and timely services and interventions across the state. The EHDI Team will then use this information to host Regional stakeholder meetings in an effort to address identified barriers and strategize ways to address them in an effort to ensure timely support and services to families.

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.

- A member of the Louisiana Hands & Voices, Guide By Your Side team was recently nominated to join the National Hands & Voices Advisory Council for Latino Family Support. She accepted this nomination and looks forward to networking on a national level in an effort to better support Latino families of Deaf or Hard of Hearing children in Louisiana. The National H&V Advisory Council for Latino Family Support provides an opportunity for Latino self-determination and leadership in Latino support. The H&V HQ Community for Latino Family Support is an important think tank to support the Advisory Council by drawing upon broad-based input from a wide range of interested participants who serve Latino families.

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 end of 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.

The Bureau of Family Health, with collaboration from YCWC members, is developing an updated version of the **Louisiana Early Childhood Risk and Reach Report** to be released later in 2020. 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.

Bureau of Family Health Adolescent School Health Program (ASHP) manages 62 School-Based Health Centers around the state, which are health centers in public and charter schools that offer comprehensive, primary and preventive physical and mental health services for student's onsite. ASHP establishes and monitors health centers' compliance with standards, policies, and guidelines for school health center operation, provides technical assistance and coordinates and encourages collaboration with other agencies and potential funding sources. School-Based Health Centers support academic achievement by working with students in a safe and confidential manner to address emotional and health barriers that hinder academic success.