

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
Oct 6, 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 to 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) is a statewide virtual center designed to ensure CYSHCN, their families, and health care providers in Louisiana have access to resource and referral services. The FRC provides community referrals, CV19 resources, health/education transition supports, and system navigation services. For resource and referral services contact the FRC team via phone 504-896-1340 or email BFH-FamilyResourceCenter@la.gov, Monday-Friday 8am-4pm.

Family Resource Center June – August 2021	
Total Client Encounters	138
Resource Needs Provided	115

Families Helping Families (FHF) – BFH Project aims to build a coordinated and family-centric statewide CYSHCN resource and referral service system utilizing the collaborative partnership between BFH-Family Resource Center and FHF Networks. FHF networks are Louisiana's statewide parent-to-parent support organization serving individuals with disabilities and children/youth with special health care needs and their families.

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. Families may contact The Family Resource Center or their local Families Helping Families Center for more information.

Transportation Assistance Program July 2020-June 2021	
34 stipends issued	Stipend expenditures \$2,778.25

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 2021 Legislative Data Report:** As specified by our legislation, we follow children who are diagnosed prior to their third birthday. Therefore, our data is not considered final and reportable until 3-3.5 years.
 - Of 179,510 children born between 2015 and 2017, 5,296 children were diagnosed with at least one birth defect, yielding an overall prevalence of 295 per 10,000 live births or 2.95%.
 - Among children with birth defects, cardiovascular system defects (50.3%) were the most common. This is a 2% increase in CHDs from 2014-2016 data reported last year. All other defects decreased.
- **BFH Family Resource Center Referral Partnership:** LBDMN is partnering with BFH's Family Resource Center to connect families to health, social, and developmental resources. Updates include development of referral logic (44 codes), report variables, and death matching; administrative support for case data entry and mailing introductory postcard; creation and approval of postcard; and development of phone scripts.
- **Prevention Case Review Project:** During our June 18 advisory board meeting, we debuted the beginnings of a prevention case review process for discussion. The purpose of the case review is to move our data to action by identifying preventable birth defects to make evidence based recommendations for systems level changes to improve prevention and intervention efforts in Louisiana's maternal health system.

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 State Newborn Screening Follow-up Program responded quickly to Hurricane Ida's disaster to ensure all infants born within the affected areas received a timely and valid

newborn screen. Staff coordinated with birthing facilities and clinics throughout southeast Louisiana to ensure proper screening and reporting of results.

- September was National Newborn Screening Awareness Month.

Sickle Cell

- September was National Sickle Cell Awareness Month. Several fundraisers and events occurred throughout the state to raise public awareness regarding sickle cell disease. Other public awareness campaigns are being scheduled for the Spring of 2022 due to the restrictions caused by COVID-19.

The Louisiana Commission for the Deaf (LCD) functions as the principal state program that provides services for individuals who are Deaf, DeafBlind, or hard of hearing on behalf of the State of Louisiana. The LCD operates as a comprehensive statewide resource center on issues relating to communications accessibility, compliance with the Americans with Disabilities Act (ADA), and other issues and services pertaining to the Deaf communities in Louisiana. The commission contracts with Regional Service Centers (RSCs) who serve as local implementing agencies which provide direct consumer services in the eight service regions for the state. The LCD staff work directly with the board commissioners, partner agencies, internal and external working colleagues, amongst others to educate; to promote, coordinate, and facilitate accessibility of all public and private services to persons who are Deaf, DeafBlind, or hard of hearing; to advise other agencies and/or organizations on the needs of Deaf, DeafBlind, or hard of hearing individuals; and to collaborate in order to identify resources that other agencies may reasonably request.

The LCD has a board. The board consists of members representing the interests of the deaf community; representatives of a state department or agency; representatives of each chamber of the legislature; and lay members appointed by the governor.

LCD Board Meeting: The third quarter board meeting was held on July 9, 2021 in the Hainkel Room at the Louisiana State Capitol. The board meeting proceeded in its usual manner, including public comments and reports and updates from the membership committee. Additional agenda items and topics of discussion included:

- Representatives from the Baton Rouge Community College (BRCC) and Louisiana Community and Technical College System (LCTCS) requesting a letter of support from the LCD Board to initiate an Interpreter Training Program (ITP) at BRCC. The Board approved a motion to submit a letter of support to the Louisiana Board of Regents on behalf of the ITP at BRCC. As a follow-up, the letter was drafted and submitted to the Louisiana Board of Regents and will continue to work with LCTCS/BRCC on this pivotal initiative.
- Jana Broussard, LCD Interim Executive Director, provided the commissioners with a legislative update. The brief update included information on the staff's continued work on a draft to update the LCD enabling statute language in addition to putting statutory language in place to improve interpreting standards in Louisiana.
- Shane Bates, LCD Program Manager, presented a budget update to the LCD Board. This presentation provided historical information on how the commission is fund, the status of Fiscal Year (FY) 2021 revenues and expenditures (as of July 2021), and a framework

outlining the amount of funds to be allotted in FY 22 in addition to the anticipated FY 2022 budgetary items.

- Shane Feldman and Davin Searls (Innivee Strategies) attended the LCD Board meeting in person. Both presented the final summary report for the identified three-year (FY 2022-2024) strategic plan and the mission, vision, and values. Now that the LCD's new mission, vision, values, and strategic priorities have been approved, the commission is responsible for identifying how the strategic priorities will be implemented and continuing the strategic initiatives work process. Following the July 9th meeting, the next steps to be taken is for the LCD executive committee to meet and assign specific commissioners to assist with the implementation of each strategic priority. The goal is for commissioners, staff, and potentially community members to participate in sub-committee meetings where each strategy will be broken down into actionable steps to identify specific objectives, tasks, the accountable person or organization, resources needed, and estimated completion dates.
- The video to the meeting can be found here: https://senate.la.gov/s_video/2021/july.

LCD Governance Training Series: The Governance Training will be a six-part meeting series. Following the adjournment of the third quarter board meeting, LCD board commissioners and staff joined Innivee Strategies consultant facilitators in the LCD Governance Training kickoff meeting. This kickoff meeting served the purpose of bringing commissioners and staff together to layout the groundwork for the expectations of each of us and begin to identify the staff that will need to be taken to achieve our strategic priorities. The first two LCD Governance Training meetings were held on August 20, 2021, and October 1, 2021 in which the group conducted meaningful conversations on the commission's accountability structures, ethical responsibilities, and day-to-day duties that ensure proper leadership and oversight of LCD in the commission's progress toward its goals and vision, along with leadership and how the roles, power and responsibilities are assigned, controlled, and coordinated. The remaining training series meetings will address the following topics:

- Workshop #3 to be held on November 5, 2021: Culture – What organizational culture consists of, how it is reinforced, and the organizational culture currently in place, as well as what culture LCD aspires to create?
- Workshop #4 to be held on November 12, 2021: Composition and Decision-Making – How to balance unity and diversity in terms of the commission's makeup and decision-making practices, as well as making decisions that preserve community trust?
- Workshop #5 to be held on December 3, 2021: Accountability and Evaluation – This will be a discussion to ensure that the commission and individuals follow through on commitments and reinforce continuous review and improvement of the commission's work.
- Workshop #6 is to be held on December 17, 2021 and will serve as the closing session.

Best Practices for Communication in Medical Settings: HCR 80 of the 2019 Regular Session of the Louisiana State Legislature set for the requirement to address Louisiana's priority need to advance exceptional experiences that deliver equitable, inclusive, and accessible experiences across the care continuum for Deaf, DeafBlind, and hard of hearing (DDBHH) individuals in hospitals and other healthcare settings. The LCD has identified the need for the development of a best practices guidebook and handbook to satisfy Recommendation #2 of HCR 80 to develop

“Best Practices for Communication in Medical Settings” for all deaf, deafblind, and hard of hearing individuals and their providers. A contractor has been procured to provide best practices and standards in line with Recommendation #2 of HCR 80 to address knowledge gaps, lack of organizational readiness amongst healthcare organizations, and other critical elements that impact the DDBHH user experience in clinical settings in Louisiana. Best Practices manual is projected to be distributed by Spring 2022.

Communications Accessibility at the Louisiana State Capitol: The LCD released a Request for Information (RFI) in July 2021. The purpose of this RFI was to identify a contractor that could provide recommendations and best practice knowledge on technology needs and hardware to address communication accessibility for individuals who are deaf, deaf/blind, hard of hearing (DDBHH), speech impaired, or others with similar disabilities or impairments. during legislative sessions at the capitol. The LCD continues to work closely with legislative staff to identify a contractor prior to the 2022 Regular Legislative Session that can fulfill the request to provide necessary technological solutions for implementation and provision of communication accommodations at the state capitol during legislative hearings.

Support Service Provider (SSP) Program: The LCD will release its Request for Proposal (RFP) for the SSP Program in October 2021. The RFP seeks to identify a contractor that will serve as the provider of support and services to DeafBlind individuals who have dual sensory (vision and hearing) loss in Louisiana.

Interpreter Service Program: The LCD is committed to enhancing and establishing interpreting standards across the state of Louisiana. We will be working collaboratively with Innivee Strategies to create a plan of action and develop a sign language interpretation framework to establish oversight and regulatory policies and procedures, based on statewide data and best practices from other d/Deaf, DeafBlind, and hard of hearing commissions’ framework.

For more information about the LCD including how to contact us, please visit our website: <https://ldh.la.gov/index.cfm/page/318>.

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 3rd Quarter Advisory Council meeting was held on July 23, 2021. Early Intervention and the support provided to families through EarlySteps were among the key topics of focus. The Council expressed interest in seeing data mapping on testing facilities across the state. Geo mapping information is being collected to share at the next convening. The 4th Quarter Council meeting for 2021 is set for Oct 22, 2021.
- In an effort to increase the number of health professionals trained on key aspects of the EHDI program a Follow-up Protocol rack card was been developed and made available

on the EHDI website. This document serves as a quick reference of EHDI 1-3-6 protocol and recommends next steps for children at various stages in the EHDI process for pediatric providers. Newborn hearing screening follow-up recommendations are outlined for infants who: 1) pass with no risk factors, 2) do not pass, 3) pass with risk factors, 4) are diagnosed as DHH. For babies who pass with risk factors, timelines for follow-up as per JCIH Guidelines are included. This summer, a mailing list of all pediatricians and family practice doctors providing pediatric services in Louisiana was collected, and Follow-up Protocol rack cards were mailed to each facility.

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.

- One of our Louisiana Parent Guides is currently serving on the National Hands & Voices Headquarters' Latino forum. In September 2021, she presented in a national virtual webinar for families entitled *Family, Culture, & Leadership- The Role of Advocacy in Raising a Child who is Deaf or Hard of Hearing*.
- Louisiana Parent Guides are continuing to receive quarterly trainings to support the work they do with families of Deaf or Hard of Hearing children in Louisiana. *Advocacy 101* and *IFSP-The Basics* were two of the trainings offered to kick off the 2021 school year.

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.

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>.

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 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 Early Childhood Comprehensive Systems 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 Bureau of Family Health's Developmental Screening Initiative created a Developmental Screening Toolkit to help medical providers integrate developmental screening services into their day-to-day practice. The virtual toolkit uses a quality improvement framework, which allows providers to systematically improve the way health care is delivered to the families they serve. It contains step-by-step information contained in webpages, instructional videos, and downloadable worksheets. Customized training to meet specific clinic needs is available at no cost to the practice through the Title V initiative. Check out the Developmental Screening Toolkit at <https://ldh.la.gov/DevScreenToolkit> to learn more.

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