Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
January 11, 2022

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. In December the center implemented a new phone and data system to support statewide reach and increase service capacity.

Beginning January 2022, FRC staff will start outreach to families of children identified through the Louisiana Birth Defects Monitoring Network to assist in linking to appropriate medical, educational, public health, and peer support resources available in their region.

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 September-November 2021	
Total Client Encounters	66
Resource Needs Provided	51

Families Helping Families (FHF) – BFH Project aims to build a coordinated and family-centric statewide CYSCHN 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. The networks recently completed round two of the statewide Specialty Provider Landscape Assessment helping to identify access points for CYSCHN pediatric specialty services. FHF Networks are currently planning spring health provider continuing education workshops aiming to build provider capacity to care for CYSCHN and developmental 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. Families may contact the Family Resource Center (BFH-FamilyResourceCenter@la.gov) or their local Families Helping Families Center for more information.

Transportation Assistance Program July 2021-November 2021	
2 stipends issued	Stipend expenditures $194.00

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. Outreach pilot is scheduled to launch at the end of January.

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 Genetics Program discussed experiences and lessons learned from its continuity of operation plan in the while experiencing Hurricane Ida during a national webinar on contingency planning for the Association of Public Health Laboratories (APHL) on December 16, 2021.
- Program staff collaborated with EHDI to coordinate a joint presentation on Newborn Screenings and Interventions for Multilingual Learners through the LA Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program through the LSUHSC on January 7, 2022.

Sickle Cell

- Bureau of Family Health staff has been working with the Department of Health, Medicaid, and Legislators on further establishing Senate Concurrent Resolution 66 to improve access to therapeutic and curative therapies as well as treatments for individuals living with sickle cell disease throughout the state.

The Louisiana Commission for the Deaf (LCD) functions as the principal state program that provides information and services to and for individuals who are Deaf, DeafBlind, or hard of hearing on behalf of the State of Louisiana.

LCD's new Mission, Vision, and Values:
Mission- To engage, empower, and enrich the lives and opportunities of Louisiana Deaf, DeafBlind and hard of hearing individuals
Vision- A Louisiana that embraces the inclusion of a diverse deaf community through full access to information, communication, and opportunities
Values- Advocacy, Accountability, Equality, Accessibility, and Sustainability

LCD Board Meeting: The fourth quarter board meeting was held on Friday, October 15, 2021 virtually. 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 American Sign Language (ASL) studies 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. No update was received during this meeting, however a full-time position for ASL studies instructor has been posted with BRCC. (since this meeting, Board of Regents has approved the ASL studies program)
- 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. Plan is for revisions to be introduced in the Spring 2022 Regular Legislative Session

- Shane Bates, LCD Program Manager, presented a budget update to the LCD Board. This presentation provided a review of common budget terminology and processes. LCD spent all of its budget authority for FY 21, and is on target to do the same for FY22.
- Jana Broussard, Interim Executive Director, provided a presentation and proposal for the creation of sub-committees to support to work of LCD's strategic priorities. Board approved. Strategic Priorities are: 1) Enhance Community Engagement 2) Modernize the Telecommunications Access Program 3) Address Gaps in Mental Health Services 4) Address Racial Disparities in LCD services 5) Establish Interpreting Standards and Systems 6) Improve Services for DeafBlind Louisianans

Priority #5- 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. This comprehensive work will begin in the Spring of 2022.

Priority #6- Support Service Provider (SSP) Program: The LCD released its Request for Proposal (RFP) for the SSP Program. 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. Award will be announced tentatively by the end of January.

Legislative Initiatives-

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. Full report will be provided by February 1, 2022.

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.

- We are proud that the first year of the COVID-19 pandemic did not substantially reduce accomplishment of our 1-3-6 goals. Due to the confusion encountered with procedures and protocols for newborn hearing screening as a result of COVID-19, as well as the fact that many clinics statewide canceled outpatient audiology appointments in the initial weeks and months of the pandemic, we anticipated a regression in accomplishment of our 1-3-6 goals for the 2020 birth cohort. While we did experience poorer rates of achievement of our 1-3-6 goals in the first half of 2020, there was some recovery in the second half of 2020. When viewing all of 2020, our screened by 1 month and diagnosed by 3 months rates are comparable to those seen in 2019, while our enrollment into early intervention by 6 months rate actually improved.

- The EHDI program developed two additional brochures for families "Your Baby Needs Diagnostic Hearing Testing- What Families Need to Know" and "An Introduction to Communication Options for Children who are Deaf or Hard of Hearing".

- Among children born in 2020 who were referred to Early Intervention (EI), 45/62 (73%) enrolled in EI by 6 months of age, which is a 25% improvement over baseline. It should also be noted that there were 14 children who enrolled in EI after 6 months of age, and 9/14 were diagnosed =/> 6 mo. 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.

- Incremental progress has been noted toward timely enrollment in family-to-family support with each birth cohort. In 2018, 43/73, (59%) of children diagnosed as DHH before 6 months were enrolled in family-to-family support by 6 months of age. In 2019, 52/75, (69%), and in 2020 44/50 (88%) of children diagnosed as DHH before 6 months were enrolled in family-to-family support by 6 months of age.

- Virtual Parent Chats continue to be held monthly for families to meet other families, to share their current needs or concerns, and gain support from one another. Families also have the opportunity to connect with Parent Guides and DHH Guides. Additionally, the Parent Chats include special speakers presenting on topics identified through the family survey.

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.

2476 families were served by MIECHV in the 3rd Quarter. Service capacity is minimally fluctuating in spite of identified challenges with recruiting and retaining families during the COVID-19 pandemic. Increases in enrollment and families keeping their visits have been noted as a result of the implementation of and flexibility associated with tele-health services.

The MIECHV Program is also continuing work with Community Advisory and Action Teams (CAATs). CAATs are made up of community members and organizations who are interested in promoting the health and safety of Louisiana's families. CAAT members share family health issues in their communities that need to be addressed, prioritize needs, brainstorm solutions, and work together with outside partners to put solutions into action. There are 13 CAATs across the state continuing to meet virtually and support and advise around the work of supporting families.

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. For more information on the YCWC contact Stacie.Trepagnier@la.gov.

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.