

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
July 8, 2021

Children's Special Health Services (CSHS) works to ensure that children and youth with special health care needs (CYSCHCN) 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) 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 Mar 2021-May 2021	
Total Client Encounters	147
Resource Needs Provided	95

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-FRC and FHF. 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. Over the last quarter each FHF hosted provider capacity building education events that offered continuing education credit for nurses and social workers. These events reached over 600 providers and community partners. Workshop topics included:

- Wellness and Mental Health - Supporting Children and Adolescents Through Covid-19 and Beyond;
- Supporting Mental, Emotional, and Developmental Health Needs of Youth and Families During Covid19 and Beyond
- Implementing Evidence-based Care Coordination Strategies into practice;
- Autism Spectrum Disorder (ASD) and Applied Analysis Behavior Therapy;
- Pandemics and Hurricanes, Ensuring the Wellbeing of CYSHCN and their families: Provider Covid19 Updates;
- Covid19 Provider Update: 2 Priorities, Vaccines and Mental Health;
- Building Blocks for a Brighter Future, Building a Strong Foundation for Children and Youth with Special Health Care Needs;
- Best practices for Autism Spectrum Disorder (ASD): Management and Therapies; and
- Best Practices and Strategies for Tele-Health and Tele-Social Care.

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-April 2021	
30 stipends issued	Stipend expenditures \$2,736.25

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. From January –May 2021, we have identified 362 children with specified birth defects born in the 2018-2021 cohort for the initial pilot.

- **Partner Updates:** Environmental Public Health Tracking Network reported an update to birth outcomes data in the health data portal <https://healthdata.ldh.la.gov/> . This includes 2005-2015 birth defects data. 2016-2017 data will be added to the portal in the July 2021 update.
- **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

- House Bill 316 proposed the addition of mucopolysaccharidosis type I (MPS I), glycogen storage disorder type II (Pompe), and Krabbe disease to the Louisiana Newborn Screening Panel to reduce the rates of mortality associated with these disorders for all infants born in the state. The bill was signed by the Speaker of the House, the President of the Senate, and the Governor to become Act No. 305 of the 2021 Regular Session of the Legislature.
- The next Genetic Diseases Program Advisory Committee Meeting is scheduled for July 23, 2021.

Sickle Cell

- Members of the Louisiana Sickle Cell Commission met on June 9-10, 2021 to focus on regional, state, and national advances in delivering care for sickle cell. Participants will be able to join the conference virtually due to COVID-19 restrictions. The Chief Financial Officer from the national Sickle Cell Disease Association of America attended the event to discuss strategic initiatives geared at staffing, finances, and grant opportunities.
- World Sickle Cell Awareness Day was celebrated on June 19, 2021. Several events occurred throughout the state to increase public knowledge and understanding of sickle cell disease, and the challenges experience by patients and their families on the international day of awareness.

Louisiana Commission for the Deaf- The Louisiana Commission for the Deaf (LCD) provides people who are D/deaf, DeafBlind, hard of hearing, and those with speech disorders with programs and services to ensure full communication access to the world around them. Staff work closely with members of the D/deaf and DeafBlind communities to continuously improve the programs and meet their needs. LCD's goals are to allow everyone to communicate fully - regardless of their hearing, vision or speech-related abilities, improve access to needed

communication supports, and to enable all people to participate in society and reach their full potential.

- Support Service Provider Program (SSP)- LCD will soon release a Request for Proposal (RFP) for the SSP Program which provides support and services to individuals who have dual sensory (vision and hearing) loss.
- Interpreter Program- LCD is committed to enhancing and establishing interpreting standards across the state of Louisiana and is engaging in the research phase of this endeavor.
- Hearing Aid Program- for eligible adults 50 years or over- LCD increased funding, to include increased reimbursement costs for hearing aid equipment
- Telecommunications Equipment Program- Currently researching new and improved assistive technology

LCD Board- LCD last public meeting was held April, 16, 2021. LCD board voted to adopt a new Mission and Vision as established by a select adhoc committee facilitated by a deaf-owned company, Innivee Strategies. Remaining 2021 meetings are scheduled for July 9th , and October 15th.

- LCD Mission- To engage, empower and enrich the lives and opportunities of Louisiana Deaf, DeafBlind, and Hard of Hearing people.
- LCD VISION- A Louisiana that embraces the inclusion of a diverse deaf community through full access to information, communication, and opportunities.
- LCD Values- will be voted on Friday, July 9th.

Additional Initiatives:

- LCD will be working this fiscal year with a contractor to develop “Best Practices for Communication in Medical Settings” for all deaf, deafblind, and hard of hearing individuals and their providers. Best Practices manual will be distributed by Spring/Summer 2022

LCD is working closely with the legislators at the Capitol to ensure accessibility to legislative session for deaf, deafblind, hard of hearing, those with speech and vision disorders. Timeline for potential implementation, Spring 2022

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.

- 2nd Quarter Advisory Council meeting was held on April 23, 2021. Early Intervention data and law revision work group work were reviewed. The remaining Council meetings for the year are set for July 23, and Oct 22, 2021.
- Earlier in 2021, EHDI piloted an In-Home Screening Project. Potential candidates were: 1) babies who did not receive an initial hearing screening prior to hospital discharge or as an outpatient, and 2) babies who did not pass newborn hearing screening and had not completed outpatient testing by 2 months of age. Of the 147 potential candidates, 35 did not have a phone number listed or the number was not working, 46 were successfully contacted by phone, and the remaining 66 were left a voicemail if possible, followed up by a text message. Forty families indicated that they would like their child to be screened through the HSP, and 33 followed through with scheduling and completing testing. The home screenings yielded the following results: 23 Passed, 6 did not pass and were referred to an audiologist for diagnostic testing, and 4 were unable to be tested and were referred to an audiologist.

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 Team is meeting monthly to partake in trainings that support the work that they do with families. *Advocacy in the Educational Setting* is one of the recent training modules completed. Monthly Parent Chats are continuing to be offered to families in a virtual setting on the first Thursday evening of each month. Parent Chat topics range from open discussions, to *Tips for Parents of Young DHH Children*, to local resources being shared by professionals working in the DHH field, and more.

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>.

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 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. It is designed to house all of the information and tools you will need to put the Louisiana Developmental Screening Guidelines into practice in one, convenient spot. 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>.