

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
Bureau of Family Health (BFH)
July 5, 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 a hybrid appointment schedule. Decisions regarding in-person vs telehealth appointment 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, 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 8 am-4pm.

Starting March 2022 FRC staff began 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. 260 families were included in a pilot LBDMN outreach. Information from this pilot will be analyzed prior to full implementation of LBDMN outreach in July 2022.

Family Resource Center March-May 2022	
New Referrals	272
Total clients served	160 (143 children)
Resource information and linkages provided to clients	679

The FRC welcomed 2 new FRC staff over the last quarter: Dr. Lenora Robinson started joined BFH in May as the FRC Manager; and Claudia Loston LPN CCHC, started as the FRC Resource Specialist in June. Over the next few months the FRC team will be working to develop a comprehensive communication plan for the FRC.

Families Helping Families (FHF) – BFH Project aims to build a coordinated and family-centric statewide CYSCSN 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. Over quarter 4 (SFY22), each FHF Network hosted spring health provider continuing education workshops aiming to build provider capacity to care for CYSCSN. The 2022 Resource Information Workshops engaged over 475 partners and providers.

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-May 2022	
11 stipends issued	Stipend expenditures \$1,427.14

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.

- **Birth Defects Data Collection Update:**
 - 2019 births- 95% complete. Will continue to identify & collect through 2022
 - 2020 births- 60% complete. 95% completion goal is 8/31/22. Will continue to identify & collect through 2023
 - 2021 births – 95% completion goal is 12/22/22. Will continue to identify & collect through 2024
 - 2022 births – 411 potential cases identified January- April 2022. Will continue to identify & collect through 2025
- **BFH Family Resource Center Referral Partnership:** LBDMN is partnering with BFH's Family Resource Center to connect families to health, social, and developmental resources. The FRC staff completed attempted contacts with 288 families of children born in 2020 with qualifying birth defects. Currently, the FRC data is being analyzed for program evaluation and to inform our recommendations for implementation. Overall, the FRC staff was very positive about the program process and contacts made with families. Affirming the need for the referral program, the necessity of earlier identification and contact with families, and our partnership in general.

- **Development of a Birth Defects Case Review Model for Prevention and Systems Improvement:**

The birth defects advisory board is developing a case review model to move our data to action by identifying preventable birth defects to make evidence-based recommendations for systems level changes to improve primary prevention and intervention efforts in Louisiana's maternal health system. The process we have developed so far includes three frameworks to support case review and two tools to facilitate case review:

- the evidence base framework as presented through literature review;
- the data findings framework which includes a State of the State for the identified birth year using a variety of state datasets and our birth defects data analysis;
- the data visualization framework (aka the maps) and subject matter expert testimony;
- the *Case Summary Form* (for individual case presentation)
- the *Considerations for Birth Defects Prevention Case Review* (to facilitate case deliberation and recommendations)

We will pilot the model in October 2022 using 2017-2019 orofacial cleft data. After any necessary revisions, we will apply the model to thirteen birth defects identified by the National Birth Defects Prevention Network as core defects.

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.

Louisiana Early Childhood Risk & Reach: 2021 Report. The Early Childhood Risk and Reach in Louisiana report is a tool designed to be used by all early childhood stakeholders, governmental and nongovernmental, to better inform policy and funding decisions that impact the distribution of critical resources.

The [2021 Early Childhood Risk and Reach report](#) describes five categories of health challenges facing Louisiana kids and families: Economic Stability; Healthcare Access & Quality; Social & Family Context; Education Access & Quality; and Neighborhood & Built Environment. The report also describes the reach of key publicly-funded programs that address these risks and challenges. Data on program reach are overlaid onto maps of overall risk, which helps to illustrate which parishes may require additional services and investments to support children's health and well-being.

Highlights include:

- 73,228 children live in the 32 parishes that are classified as either Moderate-High or High Risk, representing approximately 23.8% of all children under age 5 in Louisiana.
- Louisiana has leveraged both state and federal funds to provide access to eight key programs and services for young children: Medicaid; WIC; EarlySteps; Maternal Infant and Early Childhood Home Visiting (MIECHV); Early Head Start; Head Start; high-quality, publicly funded child care for children ages 0-3, and high-quality, publicly funded pre-K for children age 4.

- Black children face more disadvantages on average than White children, which is a result of centuries of structural racism.

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

Strategic Priority Updates-

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 March 2022 and will conclude in November 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. The award for this program will be announced as soon as the state approval process is complete.

Legislative Initiatives-

Senate Bill 98- Senator Sharon Hewitt has sponsored [SB98](#) which includes updates to the La Commission for the Deaf statute [RS 46: 2351](#), etc. Noteworthy changes include the addition of a DeafBlind Commission seat, the addition of the Office of Behavioral Health seat, and language surrounding the establishment of standards/qualifications for interpreters working in the state of Louisiana. You can track this bill using the [La Legislative website](#).

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 June 2022.

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

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 2021 annual hospital Quality Assurance Report and Newborn Hearing Screening Program Scorecard was disseminated to each of the 49 LA birthing hospitals. Scorecards highlight areas of achievement in newborn hearing screening and reporting, as well as any areas in need of improvement. This report is based on data reported to the Louisiana Department of Health Early Hearing Detection and Intervention (EHDI) program for infants born between January 1, 2021 and December 31, 2021. The Scorecard statewide average was 94%. Twenty-six hospitals scored above the statewide average, with 17 of those scoring 100%.
- The EHDI team submitted an abstract that was accepted for presentation at the 2022 Powering-Up Early Childhood conference. “Why is Early Childhood Hearing Screening Important?” The presentation will focus on periodic early childhood hearing screening to identify children with hearing losses before they exhibit developmental delays. This session will review Evidence-based hearing screening practices for young children.
- The EHDI Program goals are for infants to complete screening by 1 month, audiologic diagnosis by 3 months, and enrollment in early intervention by 6 months. Below you will find 1-3-6 data for our state’s birth cohorts of 2018 to 2020. Percentages provided for the 3 and 6 measures are among children who did not pass initial hearing screening.

EHDI BENCHMARK:	2018	2019	2020
Screened by 1 month OR before hospital discharge	99.4%	99.6%	98.9%
Diagnosed by 3 months	70.1%	73.9%	73.4%
Early intervention by 6 months	60.9%	60.2%	64.5%

We continue to achieve screening rates of over 98% each year, meeting the goal for this benchmark. Steady improvements have been made in our rates of diagnosis by 3 months of

age. Likewise, we have seen slow gains in the percentage of deaf and hard of hearing children who are enrolled into early intervention services by 6 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.

- 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.
- Training for the Guide by Your Side (GBYS) Parent Guides and Deaf/Hard of Hearing Guides was provided by National Hands & Voices trainers. Nine Parent Guides and two Deaf/Hard of Hearing guides attended the two day training which focused on providing family-to-family support centered on the needs of individual 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.

MIECHV recently expanded the eligibility requirements related to Parents As Teachers (PAT) services. Parenting families with children 36 months or younger are now eligible to enroll in PAT. MIECHV will continue to serve children up until Kindergarten entry. Services for a child entering Kindergarten will stop on September 1st of the year the child enters school. Updated outreach materials are available for use and dissemination with community partners upon request. Please contact Susannah.Boudreaux@la.gov to request updated program materials.

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 inform priorities/strategic planning across the continuum of supports/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 meets every other month on the second Tuesday of, the next convening is August 9, 2022 at 12 noon. The collaborative 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 YCWC is currently recruiting pediatric/perinatal health care providers and pregnant/parenting families interested in participating and informing early childhood systems improvement. If you or someone you know may be interested in joining the collaborative, contact Stacie.Trepagnier@la.gov for more information.

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. Locate the Toolkit at <https://ldh.la.gov/DevScreenToolkit> to learn more. The BFH, Louisiana Medicaid and the Louisiana Chapter of American Academy of Pediatrics collaborated on summer-short provider trainings that will continue through the end of July, recordings of these trainings can be located on the toolkit website. For information on the Developmental Screening Initiative and provider training requests, contact Dr. Tresa Northington at Tresa.Northington@la.gov.

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>.