Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council Bureau of Family Health (BFH) April 4, 2023

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 care coordination, 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 <u>BFH-Family Resource Center</u> provides community referrals, health/education transition supports, and system navigation services. FRC also provides 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 8 am-4pm.

Family Resource Center January-March 2023	
New Referrals	403
Total number of contacts	369
Count of Total Resource Needs Identified	1036

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.

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	
December 2022-February 2023	
1 stipend issued	Stipend expenditures \$519.17

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.

In December, LBDMN filed the 2022 annual report to the legislature, which included data reports on surveillance findings, system performance assessment and improvements, and data to action initiatives.

2022 Findings

Of 176,643 children born between 2017 and 2019, 4,657 children were diagnosed with at least one birth defect, yielding an overall prevalence of 263.6 per 10,000 live births or 2.63%. According to the CDC, the US average is about 3% of all babies born each year. Among Louisiana children with birth defects born in 2017-2019, cardiovascular system defects (about 63%) 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.

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 enroll 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.

- o Advisory Council for the Early Identification of Deaf and Hard of Hearing (DHH) Infants
 - <u>Language Outcomes committee</u>: currently focusing on standardizing the collection of outcomes for children who are D/HH in Louisiana.
 - North Louisiana committee: focuses on unique concerns related to access for families in that area of the state.
 - <u>cCMV committee</u>: reviews indicators for testing, protocol, follow up, etc. from 5 birthing hospitals in the state that are conducting targeted congenital cytomegalovirus screening. One state has universal screening in place and two others have proposed universal screening. Other states have targeted screening legislation in place, or are moving towards universal screening legislation.

- EHDI Regional Stakeholder Collaboratives: Stakeholders include parents of children who are DHH, hospital newborn hearing screening personnel, pediatric audiologists, Early Steps (Part C) providers, Parent Pupil Education Program (PPEP) DHH teachers, and Hands & Voices.
 - Recently held: Region 3 (January 2023)
 - Upcoming: Regions 2, 4, 9 (Quarters 2/3 of 2023)
- o <u>National EHDI Conference</u>: Louisiana was well represented by a diverse group at the recent annual EHDI conference in Cincinnati, Ohio.
 - Attendees from Louisiana included: EHDI program staff, Outreach teachers from PPEP, Hands and Voices Guide By Your Side Parent Guides: Parents of children identified as DHH, Deaf Guide: Deaf adult.
 - Louisiana presented a poster titled, "Hearing Aid Fitting Rates in Deaf/Hard of Hearing Children Identified in Louisiana." It can be viewed by clicking the link.

Louisiana Hands & Voices is the lead family based organization for the LA EHDI program. Guide by Your Side (GBYS) is a program from LA 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. Support is also available in the form of Deaf or Hard of Hearing (D/HH) Guides who have also received training.

- <u>Family events</u>: Opportunities for fun and family networking were held in the following areas:
 - Baton Rouge Knock, Knock Children's Museum
 - Shreveport Sci-Port
 - Hammond LA Children's Discovery Center ~ through collaboration with the Parent Pupil Education Program
- o <u>Annual Newsletter</u>: sharing Fostering Joy, a movement to celebrate the joy and magic of raising children.
- o Parent Chats: hosted the first Thursday of every month for parents whose children are identified as deaf or hard of hearing (via Zoom)
- o In the Community:
 - Louisiana School for the Deaf's Resource Fair (table)
 - Hosted a Resource Fair for families with children with hearing loss in Lake Charles area, featuring one of our D/HH Guides
 - Louisiana Academy of Audiologists (table)
 - Presented at the Louisiana Speech and Hearing Association conference
- o National EHDI conference:
 - Two Parent Guides and one D/HH Guide attended
 - One Parent Guide participated in a Parent Panel for EHDI Coordinators and other representatives

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 is also responsible for the standardizing of the American Sign Language Interpreting Profession. As such, LCD has two major announcements in this area:

1) <u>Public-Facing Interpreter Registry-</u> Louisiana Commission for the Deaf (LCD) is excited to announce its latest development of a public-facing, statewide American Sign Language Interpreter Registry in an effort to provide an easily accessible, centralized platform to identify and locate interpreters in your area!

LCD is encouraging all interpreters regardless of your availability status to join the growing roster of Registered Interpreters in Louisiana. We are kindly requesting consumers, providers, and interpreters to bear with us as we grow the list of interpreters in the state of Louisiana. Click here to <u>View the REGISTERY!</u>

2) Interpreter Needs Assessment report has been published! -This report was a compilation of a 6-month effort to better understand the current state of sign language interpreters and the services provided in Louisiana. This project was one-step toward the LCD's 2022-2024 strategic plan goals that states, "LCD will establish new systems and standards for American Sign Language (ASL) interpreting which define, describe, and incentivize new expectations for and oversight of the quality of ASL interpreters, including those in educational settings." Innivee Strategies, Inc. produced this comprehensive Interpreter Needs Assessment report on behalf of LCD. Click here to read the full Interpreter Needs Assessment report. The summarized written report can be viewed here.

More information on the LCD can be found here

BFH Maternal, Infant, and Early Childhood Home Visiting (MIECHV) is a no-cost, voluntary program that provides family support and coaching to improve the health and well-being of pregnant women and parenting families with young children. Families are paired with registered nurses or certified parent educators who provide personalized education, guidance, and referrals to services to empower families to reach their goals. Nurses and Parent Educators work with families in their homes or the family's preferred location. MIECHV implements two evidenced-based, home visiting models- Nurse-Family Partnership (NFP) and Parents as Teachers (PAT).

Services provided to participating families include:

- Health education and coaching
- Support in building positive parenting skills and caregiving confidence
- Help setting and reaching personal goals, such as returning to school or work
- Connection and referrals to services and community resources

Benefits of program participation include:

- Improved economic self-sufficiency
- Early identification of developmental delays
- Improved child health and development

Home visiting services are augmented by the MIECHV Infant and Early Childhood Mental Health Team. Through consultation, the team works with home visitors to support interactions

that promote healthy relationships in families and strengthen parents' efforts to nurture their child's social and emotional development.

In CY2022, MIECHV served 3,645 families and provided 32,754 visits. For more information about Louisiana MIECHV's NFP and PAT services, including how to get in touch with a home visitor near you, you can reach out to Susannah.Boudreaux@la.gov or visit https://partnersforfamilyhealth.org/family-support-coaching-services/.

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.

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 April 11, 2023 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 family leaders interested in participating and informing early childhood systems improvement. If you or someone you know may be interested in joining the collaborative, contact Patti.Barovechio@la.gov for more information.

The Bureau of Family Health's Developmental Screening Initiative hosts an evidence-based 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 systematic information contained in webpages, instructional videos, and downloadable worksheets. Customized training and technical assistance for implementation of developmental screening services is available at no cost to health provider practices through the Title V initiative. For information on the Developmental Screening Initiative and provider training requests, contact Dr. Tresa Northington@la.gov.

BFH Adolescent School Health Program (ASHP) has 57 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. Information on the LDH Adolescent School Health Program website can be found here.