Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council

Bureau of Family Health (BFH) July 10, 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.

- <u>Children's Special Healthcare Services</u> (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, youth health transition, 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 BFH-Family Resource Center 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. Non-English-speaking families can text their name, preferred language, and date/time that they are available between 8am-4:00pm to (504) 214-1785 or (504) 407-4601. Someone will respond in their preferred language.

Family Resource Center April-June 2023		
New Referrals	386	
Total number of families engaged	127	
Total number of outreach efforts	420	
(contact attempts to reach referred families)		
Count of Total Resource Needs Identified	598	

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 (<u>BFH-FamilyResourceCenter@la.gov</u>) or their local <u>Families</u> Helping Families Center for more information.

Transportation Assistance Program		
March 2023-May 2023		
0 stipend issued	Stipend expenditures \$0	

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. Overall prevalence of birth defects per 10,000 live births in Louisiana is 2.6%. LBDMN staff conduct active surveillance of birth defects in children born in Louisiana. According to the CDC, the US average is about 3% of all babies born each year. Among Louisiana children with birth defects, cardiovascular system defects (about 63%) were the most common. Complete findings are in the LBDMN 2022 Annual Report to the legislature.

In FFY2022, LBDMN enjoyed efficiencies resulted from strategic operational changes in FFY2020-21. From October 2021 to September 2022, LBDMN processed three birth years 2018-2020 resulting in the identification of 3,506 children with qualifying birth defects. The National Birth Defects Prevention Network (NBDPN) sets and assesses national data quality standards for population-based birth defects surveillance programs in the US. There are eleven data quality measures assessing completeness, timeliness, and accuracy attributes. Programs may achieve three performance levels: 1- Rudimentary, 2- Essential, or 3- Optimal. In 2022, overall LBDMN ranked Level 2.7 of Level 3 (Optimal), which is a slightly higher average when compared among 41 qualifying programs. LBDMN scores for each category were Completeness = 2.6; Timeliness = 2.5; Accuracy = 2.7.

LBDMN is especially proud of our improvement in timeliness. In the first assessment in 2015, Louisiana scored zero in timeliness. In 2023, we expect to achieve Level 3 Optimal in timeliness as we are processing cases within an average of 60 days of identification. This improvement is the reason that since July 2022, we identified and proactively referred 2,064 children born in 2020-2022 for one on one resource needs assessments with the Family Resource Center.

By December 2023, we expect the FRC will be processing birth defects referral cases within 90 days. This means children born in 2023 will receive a referral needs assessment consultation during their first year of life.

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.

- <u>EHDI Regional Stakeholder Collaboratives:</u> Meeting of stakeholders (including 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) to discuss regional progress on EHDI's 1-3-6 goals and strategize improvements.
 - Recently: Region 9 June 9, 2023
 - Upcoming: Region 2 TBD September 2023
- o 2022 Statewide progress on EHDI 1-3-6 Goals
 - 99.25% of infants were screened prior to hospital discharge, or as an outpatient by one month of age
 - 79% completed follow-up by 3 months of age
 - 42% enrolled in early intervention by 6 months of age
 - 78% overall enrollment

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 <u>Parent Chats</u>: 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.

Board News:

- LCD Board has voted to create a DeafBlind advisory council. If you know anyone who may be interested in joining, please have them contact LCD@la.gov
- LCD is seeking alternate funding sources for DeafBlind individuals seeking employment via La Workforce Commission
- LCD has established a Health Equity collaboration with the La Dept of Health and Bureau of Media and Communications to address equitable healthcare for DDBHH individuals
- LCD is seeking to building capacity within Department of Children and Family Services Foster Care program for children who are DDBHH and use American Sign Language
- LCD has increased its support for deaf children in K-12 Education and is working closely with the Special School District which oversees the La School for the Deaf

Other news:

- If your organization is in need of trainings, professional development, etc. related to Deaf sensitivity, culture, or services for d/Deaf, DeafBlind or hard of hearing people (DDBHH), please reach out to LCD@la.gov
- LCD will be co-hosting Community Emergency Response Trainings (CERT) in the next few months around the state for DDBHH communities, please see LCD website and or Facebook page for more information
- LCD is in the process of improving our Telecommunications Access Program (assistive technology equipment). Please be on the lookout in FY24 for new available options (no age limit requirement)

Next LCD meeting Friday, August 18th from 9am-1pm at the La State Capitol

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 wellbeing 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. During the 2023 legislative session, HB 200 (ACT 17) passed, which improves the process for adding new conditions to the Louisiana Newborn Screening Panel.

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.

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 Early Childhood Comprehensive Systems grant, Project SOAR (Screen Often and Accurately Refer). The YCWC meets every other month on the second Tuesday of, the next convening is August 8, 2023. 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 at Tresa.Northington@la.gov. BFH recently published a complementary toolkit to support providers with building effective/efficient referral processes to ensure high quality referrals when risk is identified through screening services. The Care Coordination Toolkit follows the same quality improvement framework as the Developmental Screening Toolkit. For support with care coordination program implementation, contact Kaylee.Hall@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.