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

Bureau of Family Health (BFH) January 21, 2025

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) offers a hybrid appointment schedule.
- 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 BFH Family Resource Center. CSHS-Clinical services also refers to
 other community-based organizations as appropriate.

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 Helping Families</u> Center for more information.

Transportation Assistance Program		
October 2024-December 2024		
Stipend issued: 41	Stipend expenditures: \$7,471.61	

BFH-Family Resource Center (FRC) is a statewide virtual center designed to ensure CYSHCN and their families in Louisiana have access to resource and referral services. The BFH-Family Resource Center provides community referrals, transition supports, and health/education system navigation services. Additionally, the FRC 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. Staff are available 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. Someone will respond in your preferred language.

Family Resource Center		
Oct – Dec 2024		
New Referrals	130	
Total number of families engaged	127	
Count of Total Resource Needs Identified	280	

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 FHF Networks and BFH Family Resource Center. 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.

As part of this collaboration, FHF offers annual pediatric provider trainings to strengthen the healthcare workforce capacity to care for children and youth with special health needs. Social workers and nurses can receive contact hours for attendance. The centers are busy planning spring SFY25 workshop events. Look for information on upcoming workshops posted on FHF websites, social media accounts, and email blasts.

Early Hearing Detection and Intervention (EHDI) supports coordinated systems of care that ensure families of babies and children who are deaf or hard-of-hearing (DHH) receive appropriate and timely services. The EHDI 1-3-6 goals are three-pronged. Hearing screenings of all newborns no later than 1 month of age, preferably prior to hospital discharge; for those newborns who need further testing, audiologic diagnosis should be completed by 3 months of age; and if an infant is identified as DHH, enrollment in intervention no later than 6 months of age, inclusive of opportunities for family-to-family support. The goal of the program is to ensure that children who are deaf or hard of hearing receive appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.

- Health Resources Services Administration Language Supplement and Innovation Project
 - Language assessments on children 0-3 in LA who are identified as deaf or hard of hearing (DHH)
 - Completed initial 147 assessments
 - o Beginning stages of analyzing baseline data for these language outcomes
 - o In process of completing second round of assessments
 - Will allow for examination of growth over time with collection of additional data points for children assessed a second time
 - o Results shared with families to assist with planning and goal setting
 - o Parent Focus Groups
 - Facilitated by parent leader
 - 3 held in English, 1 in Spanish
 - Identified areas of priority of LA families in the EHDI system
 - Parent survey to follow up on a wider scale regarding family priorities
 - Identification of topics that early intervention providers may need support to provide for families of children identified as D/HH

- D/HH Adult Virtual Round Table
 - o Facilitated by DHH Guides
 - o 1 meeting complete, additional to follow
 - Opportunities for DHH adults to **connect** and:
 - share their varied lived experiences
 - learn about the EHDI system
 - provide input
- Advisory Council for the Early Identification of Deaf and Hard of Hearing Infants
 - o Friday, January 24, 2025, 10:00 a.m.-12:30 p.m.
 - Bienville Building, Room 173
 627 N. 4th Street
 Baton Rouge, LA 70802
 - Meeting link for members of the public:
 - https://zoom.us/j/96482897136?pwd=bFw9Rm1wmiBohnYDqF7kabcABiRSzx.1
 - Phone: 305.224.1968 Passcode: 3siimq

More information, visit us at https://ldh.la.gov/page/LouisianaEHDI or email us at laehdi@la.gov.

Louisiana Hands & Voices provides to families of children who are deaf or hard of hearing family-to-family support. Specially trained parents, "Parent Guides," are paired directly with families who have just learned of their child's hearing condition, and provide the unique support that comes from sharing direct experience and wisdom. With support and timely resources, families can make informed decisions for their child. Another valuable resource available to families are Deaf Guides that provide families with a positive and hopeful perspective from their day-to-day, real-life experiences as a Deaf or hard of hearing person living in a predominantly hearing world. Opportunities to meet with Parent Guides and Deaf Guides are available through individual meetups, group parent chats virtually or through face-to-face group social activities held regionally throughout the state. Given the low incidence of hearing differences, parents welcome the opportunities to visit with other families of children traveling the same journey of raising deaf or hard of hearing children. More information? Facebook at "Louisiana Hands and Voices" or on the web at https://www.lahandsandvoices.org/.

H&V knows that families use many different ways to communicate with their children who are D/HH. It doesn't matter which mode of communication a family uses, H&V believes that what works for a child and their family is what makes the choice right.

• <u>Guide By Your Side (GBYS)</u> is a program from Hands & Voices that provides emotional support and unbiased information to families

Parent Guides:

- o are available to support families by listening and sharing stories about their own experiences raising a child who D/HH
- share compassion and practical knowledge as parents who have a D/HH child

o are trained to support families without bias towards any particular communication approach (e.g. spoken, sign, cued speech, combined methods, etc)

Deaf Guides:

- are specifically trained to provide support to families with invaluable perspectives that come from personal, lived experience
- are uniquely qualified and provide parents with a positive, hopeful perspective from their day-to-day, real life experiences
- give parents the opportunity to ask questions
- actively recruiting new DHH Guides! If you know someone that might be interested, please share https://handsandvoices.org/fl3/fl3-docs/FL3_DHH_Adult_Support_Training_Resources.pdf and/or email jill.guidry@la.gov

Monthly virtual parent chats on the 1st Thursday of each month from 8-9 pm. https://zoom.us/j/4770761691.

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. The <u>Genetics Program</u> also operates the <u>Sickle Cell Disease (SCD) Program</u>, 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.

• In-house testing for Lysosomal Storage Disorders As of December 11, 2024, the LDH-Office of Public Health Laboratory began screening for Mucopolysaccharidosis type I (MPS I) and Glycogen storage disease type II (Pompe). Although OPH added these conditions to the Louisiana newborn screening panel in January 2022, samples were outsourced to partner laboratories as the Newborn Screening lab implemented new instrumentation and hired new staff. Follow-up procedures for abnormal results of these conditions will remain the same.

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 64%) were the most common. Complete findings are in the Louisiana Birth Defects Monitoring Network 2023 Annual Report to the legislature.

Since 2020, LBDMN identified 3,745 children born in 2020 - 2024 who may benefit from a referral needs assessment. Currently, we are referring children under 2 years old for needs assessment/resource services.

- In 2024, LBDMN implemented a protocol to refer children who do not meet our case definition, but are at risk of developmental delay, and may benefit from a referral needs assessment.
- In 2025, LBDMN is developing and will pilot a protocol to identify infants born prematurely and refer them for a needs assessment.

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 Programs include:

- Hearing aids for qualifying individuals based on age and income
- Assistive technology for qualifying individuals, free of charge
- Support Service Providers for individuals who are deaf and blind (DeafBlind) to live and participate in their communities with independence.
- Interpreter standards, services, oversight and support for communication accessibility for individuals who use American Sign Language (ASL) and the ASL interpreter workforce

LCD has developed a Statewide Mentorship Program to elevate the quality and number of qualified American Sign Language Interpreters (ASL) in Louisiana through several key objectives:

- Providing resources and support for the ongoing professional development of ASL interpreters in Louisiana.
- Supporting the development of essential skills necessary for ASL interpreters to become highly qualified and certified professionals.
- Ensuring all Deaf, DeafBlind, and Hard of Hearing ASL users have access to high-quality ASL interpreting services to promote equitable communication access.

Training Opportunities: If your organization is interested in trainings, professional development, or resources related to Deaf sensitivity, culture, or services including ASL Interpreting for d/Deaf, DeafBlind or hard of hearing people, please contact LCD. More information on the LCD please click here or contact us at LCD@la.gov.

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

In 2024 MIECHV served 2,966 families and provided 28,095 visits. Each home visit provided represents an opportunity to strengthen family foundations, prevent future challenges, and create pathways to healthier, more stable futures.

For more information about Louisiana MIECHV's NFP and PAT services, including how to get in touch with a home visitor near you, or refer a family for services, you can reach out to Susannah.Boudreaux@la.gov or visit https://partnersforfamilyhealth.org/family-support-coaching-services/.

Adolescent School Health Program (ASHP) provides technical assistance and resources for School-Based Health Centers (SBHCs) in 25 parishes across Louisiana. Currently there are 57 Office of Public Health affiliated (SBHCs) across the state. A SBHC is a healthcare center placed within a school or on school grounds in both urban and rural communities of greatest need. All SBHC services are provided by trained Louisiana state licensed medical and behavioral health staff; which includes a medical provider, behavioral health provider, administrator, and office assistant. SBHCs allow students to manage their own health needs, receive health education, and participate in behavioral health sessions while still at school.

SBHC services are available to students who attend the school where the SBHC is located, and may include students who attend schools near the SBHC. Prior to receiving services, a parent or legal guardian must sign a consent form unless the student is of legal age to consent for services.

SBHC services include:

- Check-ups
- Physicals to play sports
- Illness and injury care
- Vaccines/shots
- Blood test
- Individual mental health counseling
- Help finding doctors and specialists outside of a SBHC and more

The Adolescent School Health Program recently:

- Launched the School-Based Health Center Registry. The 2023 regular legislative session requires SBHCs to register with the Office of Public Health. Thus far, 120 SBHCs have registered with the Office of Public Health.
- Revised the Principles, Standards and Guidelines for SBHC Operation in Louisiana. This document serves as a resource for SBHC operation.

To learn more about the Adolescent School Health Program and to obtain a list of OPH-affiliated SBHC, visit the website, which can be found here. A listing of SBHCs who have registered with the Office of Public Health can be found here.

Louisiana Provider to Provider Consultation Line (PPCL) is a no-cost provider-to-provider telephone consultation and education program to help pediatric and perinatal health care providers address their patients' behavioral and mental health needs. The program aims to increase the capacity to screen, diagnose, treat, and refer patients to supportive services by integrating behavioral health into the pediatric primary care setting and connecting providers to mental health consultants and psychiatrists.

How PPCL Works:

Any pediatric and/or perinatal provider who has behavioral health related question can call PPCL at (833) 721-2881 or request a consult by going to https://ldh.la.gov/page/ppcl. PPCL's mental health team, which includes licensed mental health professionals and psychiatrists, can provide education and support on questions regarding mental health diagnoses, medications, and psychotherapy interventions for a wide range of behavioral health needs (e.g. mental health care guides, screening forms). PPCL also provides information about mental health and other community resources that may beneficial to the patients you serve. PPCL offers training and information on pediatric and perinatal behavioral health topics and issues through its TeleECHO series, webinars, in-person training events, and website.

While not required to use PPCL services, providers are strongly encouraged to register for PPCL. For more info on the Provider-to-Provider Consultation Line, go to https://ldh.la.gov/page/ppcl.

Developmental Screening Initiative works to support pediatric clinicians with integration of universal developmental screening services into their day-to-day practice. The initiative hosts a web-based provider toolkit that assists clinicians with expanding universal developmental and perinatal depressions screening services within well child visits. The toolkit contains step-by-step guides, instructional videos, and downloadable quality improvement worksheets. It is a one-stop-shop for everything needed to implement or strengthen clinic based screening services all in one convenient spot. Please contact DevScreen@la.gov for further information.

The Early Childhood Developmental Screening Provider Survey remains open to allow providers the opportunity to submit their recommendations. The goal of the provider survey is to gain knowledge and insight about current screening practices, challenges/barriers experienced by pediatric providers, and provider recommendations for improving the current system of care. The input elicited from the provider survey will inform the Title V developmental screening initiative

work plan as well as strategies to strengthen the early childhood developmental health system in our state. Please share this opportunity with any pediatric/family medicine health providers in your network. Health providers, your input on this 10-minute survey will guide future work and policy, please consider participating. **Provider survey link:** bit.ly/4cc6zZ5.

PartnersForFamilyHealth.org Data Center disseminates products for public health practitioners, community organizations, policy makers, and researchers to guide programs and inform policy decisions. BFH has a dedicated Data to Action Team that collects, analyzes, interprets, and prepares data dissemination products. <u>Here</u> you can find reports and fact sheets on birth outcomes, mortality and injury indicators analyzed at a state, regional and parish level as well as links to websites with additional, relevant data.

The Title V Maternal and Child Health (MCH) Block Grant is the cornerstone of policy and programming for all mothers and children. Significant funding is directed toward the state's systems of care for children with disabilities and children and youth special healthcare needs (CYSHCN), to evolve and meet their unique and complex needs. The MCH Block Grant supports vital programs and services to enhance the health outcomes and quality of life for CYSHCN. Some of these efforts include:

- Improving access to family-centered care coordination
- Engaging with families and individuals with special health care needs
- Strengthening public health infrastructure
- Implementing national standards and guidelines
- Building community capacity to deliver enabling services such as American Sign Language translation services

Grant details and other Title V efforts for the CYSHCN population are available on Bureau of Family Health's <u>website</u>. For feedback or questions regarding Louisiana's MCH Block Grant, please reach out to us at <u>TitleVMCH@la.gov</u>.

Young Child Wellness Collaborative (YCWC) is a cross-agency advisory council that provides leadership and informs priorities across the continuum of supports/services within Louisiana's Early Childhood Service System. The YCWC currently serves as the State-Level advisory team for the Early Childhood Comprehensive Systems grant, Project SOAR (Screen Often and Accurately Refer) that is working with early childhood stakeholders to strengthen the early childhood developmental health system, specifically recommended early childhood developmental and perinatal depression screening services in pediatric settings.

The YCWC meets on the second Tuesday of even numbered months; the next convening is February 11, 2025. In addition to family and health providers, the collaborative includes representation from BFH program leads, the Office of Behavioral Health (OBH), Medicaid, the Louisiana Department of Education (LDOE), the Louisiana Department of Child/Family Services (DCFS), LSU Human Development Center, Head Start, EarlySteps, the Louisiana Partnership for Children/Families, the Louisiana Policy Institute for Children, and the Louisiana Chapter of the American Academy of Pediatrics. For more information about the YCWC contact Kaylee.Hall@la.gov.