

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
 Bureau of Family Health (BFH)
 March 30, 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 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 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, CV19 resources, health/education transition supports, and system navigation services. In March, the FRC staff began conducting outreach to families of children identified through the Louisiana Birth Defects Monitoring Network (LBDMN) 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 8am-4pm.

Family Resource Center	
December 2021-February 2022	
Total clients served	28
Resource needs linked to service	35

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. The networks recently completed round two of the statewide Specialty Provider Landscape Assessment helping to identify access points for CYSCHN pediatric specialty services. FHF Networks are hosting spring health provider continuing education workshops aiming to build provider capacity to care for CYSCHN and developmental disabilities.

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-March 2022	
7 stipends issued	Stipend expenditures \$685.17

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.

- **BFH Family Resource Center Referral Partnership:** LBDMN is partnering with BFH’s Family Resource Center to connect families to health, social, and developmental resources. Outreach pilot launched at the end of March with postcards mailed to 260 families alerting them to expect phone calls to assess their need for referrals to 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.

Genetics and NBS

- Effective January 20, 2022, the Louisiana Department of Health has added Spinal Muscular Atrophy (SMA), Mucopolysaccharidosis Type I (MPS I), and Glycogen Storage Diseases Type II (Pompe Disease) to the list of genetic conditions on the newborn screening panel infants are tested for at birth.
- The addition of SMA, MPS I and Pompe brings the number of conditions Louisiana screens for to 33 of the 35 conditions on the [HRSA Recommended Uniform Screening Panel](#). A list of all conditions on the Louisiana newborn screening panel can be found [here](#). More information on the new conditions can be found on the Baby’s First Test [website](#).

- Senate Bill No. 154 of the 2022 Louisiana Regular Session was introduced to the state Senate to provide insurance coverage of genetic testing for critically ill infants with no diagnosis.

Sickle Cell

- House Bill No. 163 of the 2022 Louisiana Regular Session was referred to the Committee on Transportation, Highway and Public Works to create a “Sickle Cell Disease Association” specialty license plate.
- Senate Bill No. 298 of the Louisiana Regular Session was introduced to provide the annual review of medications, form of treatments, and services for care of Medicaid enrollees with sickle cell disease. The bill will be reviewed by the Committee on Health and Welfare.

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.

- One of our greatest successes this year was being recognized as the best state website at the National EHDI conference. We have made many revisions to our website in recent years to include comprehensive information that is accessible to a variety of stakeholders, including parents and health care professionals.
- LA EHDI database users completed a satisfaction survey. Results indicated that 94% of participants were very satisfied or satisfied with the LAEHDI-IS function to search for a patient, 100% of participants were very satisfied or satisfied with the LAEHDI-IS function to enter a new follow-up services report, and 100% of participants reported that they can easily use LA EHDI-IS to achieve their intended goals.
- The EHDI team submitted two abstracts for presentation at the 2022 EHDI conference, which were both accepted. The first, “How Has the COVID-19 Pandemic Affected the Timeliness of Hearing Screening Follow-up in Louisiana?” was accepted as a poster presentation, while the second, “Factors Contributing to Late Identification of Deaf/Hard-of-Hearing Children in Louisiana” was accepted as an oral presentation.
- The EHDI team initiated a risk factor project to ensure that babies with risk factors for delayed onset or progressive hearing loss receive the follow-up audiological testing. This project has involved expanding our communications with families and PCPs to include infants who passed newborn hearing screening with one or more risk factors for late-onset hearing loss. Prior to initiation of this project, only 7.9% of children passing newborn hearing screening with a risk factor for late-onset hearing loss had reported follow-up testing. After only a few months, the follow-up rate has increased to 13.4%, a substantial improvement for such a short time period. We are continuing to correspond with families and PCPs of these children, and will monitor progress with this project. -

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 around 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.

2,123 families were served by MIECHV in the 4th Quarter. MIECHV also recently expanded the eligibility requirements related to Parents As Teachers 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 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 Early Childhood Comprehensive Systems 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 YCWC is currently recruiting pregnant/parenting families and pediatric/perinatal health care providers interested in participating in the collaborative and informing early childhood systems improvement. For more information on the YCWC contact Stacie.Trepagnier@la.gov.

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. For 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>.