

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

Bureau of Family Health (BFH)

December 11, 2019

**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.

- CSHS continues direct service clinics for CYSHCNs in regions 2 and 4-9 to meet specialty care needs in provider shortage areas. CSHS clinics are staffed by part-time physician sub-specialist, a full-time nurse, and parent liaison. CSHS parent liaisons are the parent of a child/young adult with a special health care need and work in tandem with the clinic staff to assist parents with coordination of care and linkage to community services. Additionally, parent liaisons provide emotional support, and help create family/professional collaboration within the clinic and beyond. Parent liaisons are also involved in outreach activities throughout the community, and attend mandatory quarterly trainings, to assure that the current information and services are available to families. In Regions 2, 4, and 6-9, the care team also includes a social worker that provides behavioral health and care coordination (CC) services, in Region 2 a nutritionist is on staff that provides support services for patients in other regions. OPH implemented a new electronic health record (EHR) in direct service clinics on 11/13/2019.
- CSHS sponsors CC services in six academic clinics through partnerships with Children's Hospital New Orleans (CHNOLA), Daughters of Charity, NOELA Community Health Center, Lafayette -University Hospital and Clinics, and Tulane Lakeside Pediatrics. This project provides area families access to CC services and allows residents to gain personal experience with the medical home delivery model.
- The BFH Developmental Screening (DS) Initiative continues to develop our capacity to provide implementation training and support for practices that serve the birth to five population. This includes developing an online toolkit for providers with tailored supports, providing trainings to Early Childhood Educators on general development and developmental screening tools. To date the DS Coordinator provided two of a four session professional development series for early childhood educators in Abbeville School District that addresses typical and atypical development as well as classroom-focused strategies and referral processes.

**CSHS Transportation Assistance Program** provides needed transportation assistance for families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS.

<b>Transportation Assistance Program</b>	
June - August 2019	
40 families served	Stipend expenditures \$6601.50

**The Family Resource Center (FRC)** located on the campus of Children's Hospital in New Orleans, connects Louisiana families with needed resources through outpatient clinics and the inpatient rehabilitation unit. The FRC also links families with their local Families Helping Families center for ongoing support.

Additional FRC activities:

- Supports Botox, Spasticity, Neuromuscular, Spina Bifida, Down Syndrome, Muscular Dystrophy, Cerebral Palsy and Neurology Transition clinics.
- Youth liaison supports families receiving inpatient rehab services and provides information about community/state resources.
- Provides resource information to physicians and Children's Hospital Staff and supports a campus initiative to embed resource information into the EHR.
- FRC serve on the CHNOLA Commission on Accreditation of Rehabilitation Facilities (CARF), Statewide Independent Living Council, Developmental Disabilities Council; Jefferson Parish Complete Streets Coalition, and the Region 1 MCH Regional Community Advisory and Action Team (CAAT).

<b>Family Resource Center</b>	
Resource Dissemination Activities September-November 2019	
Total Client Encounters	191
Identified Resource Needs	475
Resource Needs Met	468

**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

- LBDMN is still dealing with access issues due to the state ransomware attack. This has considerably hampered our workflow operations both internally and externally.
- The anticipated CDC announcement of a funding opportunity for Neonatal Abstinence Syndrome surveillance has been postponed indefinitely.
- Family Engagement: Julie Johnston, LBDMN program manager, also serves as Louisiana's Title V Family Representative. Julie is mom to Zac, a 26 year old with medical complexity and developmental issues. Julie has had the following opportunities to represent the CYSHCN family perspective at the system and/or program level:
  - Participated in the Administration for Community Living Listening Sessions on Emergency Preparedness for people with disabilities.

- Contacted by Peggy McManus, co-director of Got Transition at the National Alliance to Advance Adolescent Health about our personal health transition story and to review provider resource lists and new 6 Core Competencies. Will set up an interview at a later date about navigating multiple transitions.

**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

- The Genetic Diseases Program Advisory Committee Meeting was held on October 25. The advisory committee discussed the current membership, legislative mandates, proposal to add four new conditions to the newborn screening panel, and the meeting schedule for 2020.
- The Genetics Program and the OPH Lab are collaborating on the NEWSteps Continuous Quality Improvement Project funded by Association of Public Health Laboratories (APHL). The project will focus on the turnaround time from newborn screen sample collection to the reporting of the result to the Primary Care Provider.

#### Sickle Cell

- The 2018 annual report for the Louisiana Sickle Cell Commission was submitted to the Louisiana Legislature. The report highlights the activities from the past year and future objectives.
- The Louisiana Sickle Cell Commission Quarterly Meeting scheduled for December 10 has been postponed due network and computer issues impacting the state system. The next Commission meeting will be rescheduled for early 2020.

#### **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.

#### **Hearing Speech and Vision - 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.

- In an effort to identify additional needs of families of children who are deaf or hard of hearing, a parent survey was developed. This survey was sent out to approximately 500 families of children who are deaf or hard of hearing and 82 families responded to the survey. Two questions about communication options were included in this survey. The first question was “Were you offered information on the following communication options? (Check all that apply)”. The number of respondents indicating they were offered information on the following communication options was (32) American Sign Language, (31) Listening and spoken language, (22) Total communication, and (12) Cued Speech. Also, (9) families indicated they did not want any information and (23) families indicated they were not offered any information. The second question was “Who shared information with you about different communication methods? (Check all that apply)”. The number of respondents indicating who shared information on communication methods was (45) EarlySteps provider, (38) PPEP teacher, (29) Audiologist, (27) (Speech therapist, (13) Hands & Voices GBYS Parent Guide, (12) my child’s doctor, (10) other, and (1) a deaf person. Also, (17) families indicated that no one shared information. As evidenced in the survey responses, information about all communication options is not consistently being offered to families, and the information is being shared by a variety of sources. There was an identified need for all families to have an option to receive information about the spectrum of communication options presented to them in a consistent and unbiased manner.
- In response to the survey data, the LA EHDI Program provided a workshop entitled “Family Centered, Strength-Based Early Interactions”. This training took place on October 17<sup>th</sup> featuring speaker Karen Hopkins, the Director of the Statewide Deaf and Hard of Hearing Service Center in Maine. Early Steps Providers, Parent Guides from the Guide By Your Side Program and staff from the Parent Pupil Education Program participated in this event. During the training participants had the opportunity to learn about the Model used in Maine that provides coordinated supports for families of newly identified DHH children as well as learn a variety of strategies used to share communication opportunities with families in an unbiased way. The October 17<sup>th</sup> training was a great learning and networking opportunity for participants and will serve as a launching point for planning next steps.
- Materials and a plan for dissemination need to be determined to ensure that families are receiving information about communication development for deaf and hard of hearing children in a systematic and deliberate manner.

**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.

- Members from Louisiana Hands and Voices Chapter recently attended the National Hands and Voices Conference in Washington DC. Family leaders came

together from all over the world to attend this conference and to develop skills and receive training on how to provide leadership to others while affecting systemic change where they live. The conference is devoted exclusively to training family members, with children who are deaf or hard of hearing, to be effective agents of change. Information gained at the conference will be shared with Louisiana GBYS Parent Guides and Deaf or Hard of Hearing Guides in an upcoming training and will be used to support the way Guides serve and connect with families in Louisiana.

**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. SFY 2019 reach data coming soon.

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.

*Nurse Family Partnership (NFP):*

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI- eligible first-time moms and families from pregnancy until the child's second birthday.
- NFP serves moms living in all parishes except Caldwell, East Carroll, Madison, Tensas, Union, and West Carroll.

*Parents as Teachers (PAT):*

- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI- eligible expectant or parenting families from pregnancy until the child enters kindergarten.
- PAT serves families living in Northern Louisiana and the New Orleans area.

<b>Maternal, Infant, and Early Childhood Home Visiting Program</b> SFY 2019 Reach		
Nurse Family Partnership	3,248 families served	33,565 home visits
Parents as Teachers	763 families served	7,063 home visits

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>.

**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 formerly for the SAMHSA-funded Project LAUNCH grant. The YCWC includes representation from BFH, EarlySteps, the Office of Behavioral Health (OBH), Louisiana Department of Education (LDOE), Department of Child and Family Services (DCFS), Medicaid, LSU Human Development Center, and Office of Government Affairs.

YCWC Workgroups:

- Family Engagement & Leadership
- Early and Accurate Identification
- Early Childhood Data System Integration

**Bureau of Family Health Adolescent School Health Program (ASHP)** manages 62 School-Based Health Centers around the state, which are health centers in public and charter schools that offer comprehensive, primary and preventive physical and mental health services for students onsite. ASHP establishes and monitors health centers' compliance with standards, policies, and guidelines for school health center operation, provides technical assistance and coordinates and encourages collaboration with other agencies and potential funding sources. School-Based Health Centers support academic achievement by working with students in a safe and confidential manner to address emotional and health barriers that hinder academic success.