Office of Public Health Report to the DD Council

September 2016

Bureau of Family Health (BFH) news: Title V programs had a very successful Title V Block Grant Review in Dallas Texas on August 23, 2016. The Title V Block Grant provides a backbone of funding for MCH and CYSHCN programs in the BFH. CYSHCN Programs are now under BFH under the direction of Amy Zapata. Efforts are underway to coordinate programs for greater impact. Two joint initiatives focused on national performance measures include:

- Developmental Screening: CSHS and BFH are working to increase developmental screening rates in Louisiana so that children with developmental delays can be identified and referred to Early Steps as soon as possible. Early intervention will improve outcomes!
 - The developmental screening workgroup has identified optimal screening tools for children from birth to 5 years to detect not only delays in developmental milestones, but also risk of maltreatment or abuse and social emotional problems as well.
 - The workgroup is developing a plan for dissemination to medical providers, Early Steps providers, and other programs that conduct developmental screening.
- Insurance coverage: While LA enjoys high insurance coverage rates among children and CYSHCN, and coverage for adults is rapidly improving with Medicaid expansion, gaps in coverage exist. This initiative will provide education to BFH staff on general insurance terms and plans as well as specific Medicaid plans. Families needing information about Healthy Louisiana Plans will be referred to the Bayou Health help line: 1-855-229-6848.

Children's Special Health Services:

- Family Resource Center (FRC) at Children's Hospital, New Orleans
 - The FRC continues to provide statewide community-based resource information to clients: June-August 2016: 287 total client encounters; 435 needs identified; 434 resource needs met
 - The FRC maintains its Advisory Board with >50% of members parents of CYSHCN. The next Advisory Board meeting is October 11, 2016.
 - FRC conducts community outreach:
 - Jefferson Community Health Center Clinic Marrero/Health Education Forum was held July 28. The event provided families with brochures, fact sheets, FHF webinars and workshop flyers to educate families about FRC and FHF services.

- FRC Youth Liaison activities: Steven Nguyen
 - Participates in the OCDD Systems Transformation Stakeholders group monthly via conference call and in person.
 - Participates in the Community and Family Support System Task Force of the Louisiana Developmental Disabilities Council. This task force will meet 3 times before September to review the current state of supports and services made possible by Act 378 of 1989 and make recommendations to improve and sustain the system to state policymakers.
 - Attended the Spina Bifida National Conference in Bloomington, MN on June 24-28. Travel expenses were paid by Spina Bifida of GNO.
 - Visits families receiving inpatient rehab services and encourages them to visit the FRC. The FRC links patients with FHF in their home region of the state.
- Transportation Assistance Program (TAP):CSHS continues to provide needed transportation assistance to families when Healthy Louisiana transportation is not available or practical. Most stipends cover travel out of parish to Children's Hospital New Orleans or Shreveport; May-August 2016 travel stipends were provided to 47 families totaling \$5,848.28.

• Medical Home—Care Coordination and Transition education

- CSHS program staff continue to educate LSU pediatric residents on rthe importance of medical home, care coordination, and developmental screening for CYSHCN
- CSHS staff participate in LSU HDC Leadership in Neurodevelopmental Disabilities seminars to educate graduate students and family members on Title V, medical home and care coordination.

Resource Information Workshops:

- July 14, 2016- An RIW was held in Monroe at Kitty Degree School of Nursing on the campus of UL at Monroe
 - 94 attendees, including nurses, social workers, and state agency reps
 - In addition to resource presentations, the workshop included CE presentations by the CSHS Social Worker and CC Supervisor on Care Coordination and Youth Health Transition
 - Door Prizes included gift cards, TV (grand prize) donated by Jim Sprinkle and FHF at the Crossroads

- Future RIWs: February (Lafayette) and September (Shreveport) 2017. DD Council members are encouraged to attend. RIWs feature regional resources and provide nurse or social worker CE. Email me for details the month of/before the event: susan.berry@la.gov
- Clinical Activities: CSHS continues to provide 22 safety-net subspecialty clinics in Regions 2-9 for CYSCHN that meet medical and financial eligibility. Clinics provide subspecialty care, family support, and care coordination that is coordinated with the medical home. Subspecialties include orthopedics, neurology, ENT, cleft lip and palate, cardiology, cystic fibrosis, and ophthalmology. Audiology clinics provide hearing aids in regions with no private audiologists that provide hearing aids (Regions 5 and 8).

Louisiana Birth Defects Monitoring Network (LBMDN): The Louisiana birth defects surveillance system provides data that are used to determine the prevalence of birth defects in Louisiana, which can be used to help determine causes, target prevention efforts, and link families with resources.

- **Zika CDC Grant:** LBDMN was awarded one of 40 CDC grants to provide rapid surveillance, intervention and referral to services for infants with microcephaly or other neurologic manifestations born to mothers infected by the Zika virus. The grant received an outstanding score of 93/100. LA received the maximum award of \$400,000 over 5 years. The grant began August 1.
- **LBDMN** is conducting a retrospective analysis of 2013-2015 cases of microcephaly to obtain baseline data. Microcephaly was taken off the list of birth defects included in the surveillance system in 2012 by CDC, but has now been added back in to help monitor congenital Zika infections. To date, all cases of Zika in infected women are travel related and no mosquitos in Louisiana have been found to be infected. As of this writing, no infants have been born in Louisiana with microcephaly or known neurologic manifestations of Zika infection.
- Fight the Bite! Use DEET insect repellent when outdoors even during the daylight hours. Drain standing water around your house. Avoid travel to infected regions. Practice safe sex and pregnancy planning. See CDC Fact Sheets http://www.cdc.gov/zika/fs-posters/

Hearing, Speech and Vision:

Vision Program: At the end of December 2015, the HSV Program lost one of its two vision contractors to a sudden, health-related death. Jeff Robinson had been the Louisiana Lions Eye Foundation Cubsight State Coordinator for 25 years and built the Cubsight program into a primary health service for LA children, working with daycares to provide vision screening and needed referrals for children statewide between the ages of 11 months and 4 years. Recently a new Cubsight Coordinator was hired, Cherie Foret. For more information contact John Carlone, Executive Director of the Lions Eye Foundation at 504-251-2508.

Early Hearing Detection and Intervention:

- Parent driven support groups: Louisiana Hands and Voices and the Guide By Your Side program, support groups for deaf and hard of hearing children and their families, are becoming increasingly active statewide. Thanks to federal carryover funding, 4 of our parent leaders will be attending the 13th Annual Hands and Voices Leadership Conference the end of this month in Colorado.
- CMV and Hearing Loss: Several members of the LA EHDI team will be attending the Congenital Cytomegalovirus Public Health & Policy Conference, Sept. 26 & 27 in Austin, Texas. CMV is now considered the most common cause of congenital hearing loss. The goal of the conference is to present the latest research on diagnosis and treatment, raise awareness, improve prevention and early intervention, and disseminate family support resources. The EHDI team looks forward sharing the information with other professionals.
- The first annual Louisiana Academy of Audiology meeting was held September 11-13 in New Orleans. Four members of the EHDI team presented LA EHDI updates. In August, team members attended the Louisiana Chapter of the AAP meeting in Shreveport and shared EHDI information with attendees.

Genetics:

Newborn Screening:

- Severe Combined Immunodeficiency (SCID) testing will begin in 2017. Medicaid has agreed to begin reimbursing the program for SCID testing in FY 18.
- The program is working with the Association of Public Health Laboratories (APHL) to write a blog regarding the newborn screening program activities during the August 2016 Flooding Event in Louisiana

Childhood Lead and Healthy Homes:

• In July the program was awarded a \$1.1 million dollar Lead Based Paint Hazard Control Grant. The purpose of this grant is to remediate 125 homes of children with elevated blood lead levels where the source of lead poisoning is lead based paint. More information can be found at:

http://portal.hud.gov/hudportal/HUD?src=/press/press_releases_media_advisories/2016/HUDNo_16-112

• The program is working with partners to plan for Lead Poisoning Prevention Week (October 25-28). A list of events is forthcoming.