

Office of Public Health
Quarterly Report to the Developmental Disabilities Council
December 2014-February 2015

Children's Special Health Services:

The Family Resource Center (FRC) *continues to provide community based resource information to clients.* During this past quarter there were 180 Total Client Encounters, 508 resource needs identified, and 414 resource needs met (81%). The FRC Social Services Counselor, Claire Brown, and Parent Liaison, Thuy Nguyen, provided direct services in Botox, Spasticity, MD and neuromuscular clinics. Youth liaison, Steven Nguyen, continues to provide community resource information to families in inpatient rehab: FHF contact information, CSHS FRC brochure and information and CSHS statewide resource list. Families are also given promotional items including medical record holder, flash drive with state resource information, sling pack, bags and pens. Families in the rehab unit are encouraged to visit the FRC during their stay at Children's for further assistance with identifying supportive resources in their home town.

The FRC continues to maintain its Advisory Board. During the November 20, 2014 Advisory Board Meeting several topics were recommended for CHNOLA educational programs. These include:

- LATAN program (scheduled March 4, 2015)
- Hab program---504 Services for Children with Chronic Illnesses (planning meeting March 11)
- Resource Fair for CHNOLA staff featuring agencies that serve CYSHCN
- CE program for nurses and social workers—Youth Health Care Transition
- Broadcast 16th Annual Chronic Illness & Disability Conference from Baylor

The next Advisory Board meeting is planned for April 21, 2015.

FRC staff continue to participate on local and CHNOLA boards and committees: Thuy, our parent consultant, participates in the CHNOLA CARF Outcomes committee, providing family input. She is able to provide information to staff that will ultimately assist in getting resource information to families; Steven, our youth liaison, is a member of the OCDD Core Advisory group that is making recommendations for changes to the Waiver. Steven began participating in *Partners in Policymaking* that began in January 2015.

Transportation Assistance Program: CSHS continues to provide needed transportation assistance to medical appointments for families of CYSHCN . During November 2014-January 2015, travel stipends were provided to 87 families in regions 4, 6, 7, and 8 totaling \$13,284.57.

Medical Home—Care Coordination (CC) and Transition: The CSHS Statewide CC Supervisor provided ongoing telephonic technical assistance for contracted academic Care Coordinator/Medical Home practices, collaborated with CSHS Executive Team on CC toolkit for practices, and continued to update regional resource binders and identify new CC resources for practices. She also attended the New Orleans NCQA content expert conference on Patient Centered Medical Home Feb 4- 6. After completion of the test, she will be certified as an NCQA content expert on medical home certification for practices. She is currently offering “Lunch and Learns” to private practices on four important topics on caring for CYSHCN. The one hour sessions offer CME for nurses and social workers on “medical home”, “transition to adulthood”, “care coordination” and “developmental screening.”

The Title V CYSHCN Director and the CC Supervisor presented their CC model at the annual AMCHP conference and distributed CC Toolkits. Both were well received. They will meet with Louisiana Healthcare Connections executive team in April to discuss possible piloting of the CSHS care coordination model in LHC pediatric practices.

The Title V CYSHCN Director (Dr. Berry) continues to direct both the LSU and Tulane Development Rotations for pediatric residents. Most of the didactic sessions for this mandatory rotation have been replaced with the DD Council sponsored webinars. The webinars are not yet posted for CME for private providers however due to delays in the credentialing process.

Title V Block Grant and Statewide Needs Assessment: The Title V Block Grant to states is undergoing major transformation by HRSA to streamline initiatives to better demonstrate impact. Under Title V, 30% of the block grant federal dollars must be spent on CYSHCN. States must also provide a state dollar match with a 4:3 federal: state ratio. Until now, the CYSHCN activities were centered around 7 National Performance Measures. For the next cycle, activities must focus on at least 2 of only 4 National Performance Measures: medical home (including care coordination), transition to adulthood, developmental screening from age 10-60 months, and insurance coverage for CYSHCN. In addition, next year we will be asked to select 1-2 State Performance Measures based on CYSHCN needs identified in Louisiana.

To select NPMs and SPMs, each state must conduct an in-depth Needs Assessment that will be submitted with the new grant In July. Strategies will then be identified to improve Louisiana’s selected NPMs and SPMs over the next 5 years.

For our 2015 Needs Assessment, CSHS contracted with The Policy and Research Group (PRG) to conduct 10 focus groups of caregivers of CYSHCN in Regions 1, 2, 6, 7, and 8. Focus groups were held in December and results have been submitted to CSHS. Two groups were held in each region—one with families recruited through CSHS clinics and one with families recruited through Families Helping Families. CSHS also collaborated with PRG to administer a survey to pediatricians and family practitioners from December 1, 2014-January 20, 2015. The purpose of the survey was to gather information on the medical care practices of pediatricians and family medicine physicians who provide services to children and adolescents in Louisiana. 315

physician surveys were completed for a response rate of 23.5%. Needs Assessment final results will be presented to the DD Council and published in AAP Progress Notes and the LAFP newsletter. MCH and CYSHCN Programs will hold a stakeholder meeting in April to assist with identification of the top 10 priority needs of the MCH and child populations in Louisiana and to begin to identify performance measures and strategies.

Electronic Health Record is coming to OPH! Trainings have begun in Success EHS. Full implementation is expected by June.

Louisiana Birth Defects Monitoring Network (LBDMN): Louisiana's birth defects surveillance system is funded by the Title V Block grant and a CDC grant. In January 2015, LBDMN submitted the 12 month continuation application for the CDC grant. We were awarded the requested amount of \$183,934.00 for the period February 1, 2015 – January 31, 2016. The next four year grant will begin in 2016. LBDMN has provided active surveillance for birth defects statewide since 2008. The surveillance system provides data that is helpful for prevention and education strategies.

As of February 2015, 53 of 56 birthing hospitals have begun submitting discharge reports electronically through our Secure File Transfer Protocol (SFTP) site. This permits data collection specialists to receive uniform hospital discharge data securely, greatly increasing the efficiency of the surveillance system. The program is working with the remaining sites to urge compliance.

LBDMN integration with vital records through LEERS has been delayed due to delays in contract amendment approval. As of February 5, 2015, Vital Records reports the contract is in process. Case ascertainment will be increased by expanding data sources to include Louisiana Hospital Inpatient Discharge Data (LAHIDD). Active surveillance continues for three years before a birth cohort is considered complete. The updated 2008-2011 birth data will be submitted to the National Birth Defects Prevention Network (NBDPN) in May 2015 and to Environmental Public Health Tracking in June 2015.

ICD-10 Implementation is slated for October 2015. LBDMN is piloting ICD-9 to 10 dual-coding review projects with Ochsner Main Campus and East Jefferson General in preparation for transition.

LBDMN Program Manager, Julie Johnston, presented on a panel to train providers in Emergency Preparedness for CYSHCN at the AMCHP conference in January 2015. Julie continues to participate in the AAP's Children with Disabilities subcommittee to develop Emergency Preparedness for CYSHCN guidance for pediatricians and families. Draft educational handouts were circulated for review in February 2015. Julie serves as the Family Advisory Network Representative to Louisiana's Emergency Medical Services for Children which meets on March 25, 2015. On March 24, 2015 Julie will participate on an annual panel of CYSHCN parents who speak to students in Delgado Community College's Occupational Therapy Assistant Program. Julie has represented CSHS interests in several advisory meetings regarding the transition to managed care for CYSHCN both in Medicaid and Long Term Supports and Services in February and March 2015.

January 2015 is National Birth Defects Prevention month. The 2015 theme is "Making Healthy Choices to Prevent Birth Defects - Make a PACT for Prevention."

NBDPN's goal for 2015 is to continue to increase awareness that birth defects are "Common, Costly and Critical" and to offer steps that can be taken by professionals, community groups, and the public to prevent birth defects. Some of the new resources include sample letters to health care providers, a factsheet for policy makers, resources for grandparents of children with birth defects, and tailored materials for local health department. The electronic package was shared with more than 300 partners and stakeholders in all Louisiana public health units, school –based health centers, federally qualified health centers, all CSHS contract providers, and student health centers of all universities and colleges. In addition, the electronic version of the package will be sent to peer support organizations for electronic distribution to their constituents through their social media networks. The materials can be accessed at <http://www.nbdpn.org/bdpm2015.php>

GENETICS: Integration of the Newborn Screening results with Vital Records through LEERS is progressing. The program is working on the best procedure to train facilities on the new module. Piloting is anticipated for summer 2015.

Sickle cell disease is a chronic condition that causes stroke, retinal detachment, organ failure, and other disabilities, primarily in the African American population. The sickle cell program is compiling a list of all patients diagnosed with sickle cell disease through Louisiana's newborn screening program. This list will be used to establish a sickle cell registry that the Louisiana Sickle Cell Commission can use as an outreach tool to improve care of sickle cell patients across the state.

CHILDHOOD LEAD & HEALTHY HOMES: Primary care physicians in Louisiana are mandated to test all children for lead at ages 12 and 24 months. Because this has not happened consistently, testing for lead was started in WIC clinics on October 1, 2015. Since then, over 500 children have been tested. Of those 79% were tested for the first time and might not have otherwise been tested.

Recently, some Mardi Gras beads have tested positive for lead. On January 14, 2015, the program launched a "Have a Happy and Lead Safe Mardi Gras" campaign to teach parents how to keep their children lead-safe along parade routes. This information was shared via a bookmark that explained to parents the importance of wiping children's hands before eating and after picking up beads off of the ground, washing and rinsing beads that were picked up off the ground and promptly changing children's clothes when returning home from parades.

Louisiana's Early Hearing Detection and Intervention (LA EHDI) Program of Hearing, Speech & Vision is preparing to train providers how to access hearing screening and assessment results online through the newly launched web-based EHDI Information System. The new system, funded by a cooperative agreement with the CDC, will enhance the capacity of the current LA EHDI-IS to collect screening, diagnostic and early intervention data in order to ensure that children and their families receive quality services, assess Louisiana's progress toward meeting national EHDI objectives and goals and ensure the validity of reportable information. Physicians, audiologists and other approved and registered users will be able to access patient information in a timely, safe and protected manner. Stay tuned for more information.

Several members of the LA EHDI team recently attended the national EHDI conference in Kentucky, where the LA web page was named as one of the top five EHDI websites in the nation. The website includes special tabs and sections for the medical home, audiologists, birthing facilities, families and early intervention as well as electronic versions of all program-created guidelines, brochures, and forms. There is also an easy to use "Find an Audiologist" section with a click-on map that helps to find an audiologist in any area of the state. Please visit the website at www.ehdi.dhh.la.gov.

The team also submitted abstracts to the meeting planning committee and 3 were chosen for presentation at the meeting: *Reducing Loss to Follow-Up: Do It the PDSA Way; Why Does It Take So Long to Complete the Audiologic Process?*; and *Factors Associated with Late Hearing Screening and Late Diagnosis of Hearing Loss in Early Childhood*.