

## Office of Public Health Report to the DD Council

September 2015

### 2015 Title V MCH Block Grant Review:

- Louisiana hosted a successful Title V MCH Block Grant Review on Tuesday, August 25<sup>th</sup>. Title V provides the backbone of support for Bureau of Family Health (BFH) and Children with Special Health Care Needs (CYSHCN) programs. 2015 marked the beginning of a new 5 year grant cycle, greatly revised grant guidelines, and the completion of the 2015 Needs Assessment that is the basis for activities for the next 5 years.

The Region VI Project Officer and two reviewers gave positive feedback on the state's needs assessment process and report, as well as the block grant report and application. The day-long review was attended by CYSHCN Programs and Bureau of Family Health (BFH) staff. CCPH leadership (Dr. Takeisha Davis and Matthew Valliere), and OPH leadership (Beth Scalco) attended for a portion of the day as well. A recap of CYSHCN Needs Assessment highlights will be presented at the next DD Council meeting.

### Children's Special Health Services:

- **CSHS will host a Greater Baton Rouge Resource Information Workshop** October 20, 2015 at the Jones Creek Library from 9AM-2PM. It will include 2 CE offerings: Care Coordination and Youth Health Transition. RIWs are opportunities for various agencies and programs to present their services for families of CYSHCN including eligibility, services, and application information to other agencies that serve CYSHCN. In addition, this RIW will feature 2 free CE offerings on Care Coordination and Transition to Adulthood for nurses and social workers. Keep your eyes open for upcoming RIWs in your area!
- **CSHS Annual Resource Mail Out:** In August CSHS mailed public health and community based resource information to a combined total of **442 partners** including FQHCs, school-based health centers, private physician offices, and school nurses. The resource information provides updated contact information for resources most commonly used to support families of CYSHCN. CSHS hopes to help facilitate coordination of referrals between agencies.
- **Transportation Assistance Program (TAP):** CSHS continues to provide needed transportation assistance to families for medical appointments where Medicaid/Bayou Health transportation is not available; June-August 2015 travel stipends were provided to 66 families in regions 4, 5, 6, 7, 8, and 9 totaling \$8,663.
- **CSHS continued to support care coordination in academic practices** and to assist with the development rotation for LSU and Tulane pediatric residents

through medical home presentations, family visits and interviews of parents of CYSHCN through Operation Housecall, and learning about community and public health resources. The goal is to produce physicians who are more sensitive to the needs of families of CYSHCN and more competent in caring for them.

- **Family Resource Center at Children's Hospital, New Orleans:**
  - The FRC continues to provide community-based resource information to clients: June-August 2015: 285 total client encounters; FRC staff continue to provide direct services in Botox, Spasticity, MD, neuromuscular, Down Syndrome, and Spina Bifida clinics at CHNOLA. The FRC youth liaison continues to provide community resource information to families in inpatient rehab.
  - The FRC hosted a **Resource Fair** for health care staff at CHNOLA on June 24, 2015; over 150 staff and 44 vendors attended. This was so successful that it will become an annual event!
  - On August 5, 2015, the FRC hosted a **CSHS CE Program** for nurses, social workers, and therapists: **Youth Health Care Transition**, 44 staff attended.
  - The FRC maintains its Advisory Board, comprised of families (>50%) and agencies that serve CYSHCN. The next Advisory Board meeting will be held October 6, 2015.
  - Steven Ngyuen, the Youth Liaison, completed Partners in Policymaking class in June 2015.
  - The FRC will broadcast the 16th Annual Chronic Illness & Disability Conference from Baylor for CHNOLA physicians and staff on October 1 & 2, 2015. This year the conference will offer free CME and CE.
- CSHS continues to provide **22 safety-net subspecialty clinics** in Regions 2-9 for CYSHCN 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 take 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. LBDMN hopes to pilot its new (but delayed) software system in October, which will be auto-populated by vital records data. This will auto-generate letters to families of infants with certain types of birth defects to link them with resources in their area of the state, including FHF and CSHS clinics. This will be an exciting advancement in helping families navigate the resources they need.

Prevalence data for LBDMN are gathered until a cohort is 3 years old. Hence, the 2008-2011 birth cohorts were complete in 2014 and entered into the system in 2015. This data was submitted to CDC in May and to Environmental tracking (for GIS mapping) in June. This year the program hopes to achieve its first regional profiles of birth defects prevalence rates.

### **Hearing, Speech and Vision:**

- The newborn screening program implemented its **web-based database** one year ago, and has since developed webinar trainings for providers to access and enter screening, assessment, and intervention data (similar to the LINKS immunization system). To date, 106 providers have been trained to enter and retrieve data through the system. This will greatly improve follow-up of infants with positive screens for hearing loss. Louisiana had already achieved better follow-up than most states because of its effective family involvement. Recent CDC site visitors commented that that the LA software system is one of the most thought out, thorough and impressive systems they have seen thus far. MOUs are currently being finalized with EarlySteps, WIC and other OPH programs to reduce the number of infants lost to follow-up and help meet the goal of beginning early intervention by 6 months of age.
- In early spring, LA EHDI will host advocacy training to parents, deaf and hard of hearing (D/HH) persons and professionals working with children with hearing loss. **Advocacy Support and Training program (ASTra)** is an intensive educational training focusing specifically on D/HH educational advocacy that covers the fundamentals of special education law, including advocacy strategies and case law. ASTra training is provided with a commitment to unbiased support to families, regardless of language and communication approaches used by their children. For more information, contact Terri Ibieta at 504-554-5980.
- The LA EHDI team is planning a **statewide conference for early interventionists, parents, audiologists, D/HH individuals and professionals working with children who are D/HH**. The main topic of the conference will be the Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation that a Child is Deaf or Hard of Hearing. This document is a supplement to the recommendations in the year 2007 position state of the Joint Committee on Infant Hearing (JCIH) and provides

comprehensive guidelines for EHDI programs on establishing strong early intervention (EI) systems with appropriate expertise to meet the needs of children who are D/HH. For the infant or young child who is D/HH to reach his or her full potential, carefully designed individualized intervention must be implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices and proven models. For more information on either of our upcoming conferences, contact Terri Ibieta at 504-554-5980.

### **Genetics:**

- Jantz Malbrue was hired earlier this year as program manager for the **Sickle Cell Program** to work with the Sickle Cell Commission and the Sickle Cell Foundations to develop a more comprehensive, coordinated system of care for people with sickle cell disease. SS Disease can be very disabling in adults who are more prone to strokes and infections. Jantz completed site visits to the 5 sickle cell foundations across the state and will now begin working on a standard of care plan for the foundations to follow for all sickle cell patients.
- The CDC awarded the Office of Public Health a \$210,000 grant per year for two years to implement **newborn screening for Severe Combined Immunodeficiency (SCID)**. SCID causes life threatening infections unless treated early with a stem cell transplant. Implementation of SCID testing will increase the number of conditions on the Louisiana newborn screening panel to 30 (including Hearing and CCHD). The only recommended condition not yet on the Louisiana panel is Pompe's disease, a lysosomal storage disease that effects the heart and muscles and can cause death in the first year of life, unless treated early with enzyme replacement therapy. SCID screening is anticipated to begin in November of 2016.
- **Childhood Lead and Health Homes:** Louisiana has high levels of lead contamination of soil, especially in inner cities, from peeling paint of old houses. When lead is ingested by toddlers, it can cause learning disabilities, poor impulse control, and symptoms of ADHD. High levels can cause seizures and death. The Louisiana Childhood Lead Poisoning Prevention Program (LACLPPP) aims to increase screening for lead in children at 12 and 24 months of age. October 26-30 is Lead Poisoning Prevention Week, which includes many educational activities to increase awareness, including a walk around the Mercedes Benz Superdome. Watch the LACLPPP website for details as the program for the week evolves!
- The Program is assisting Steven Weil with the National Healthy Homes Conference which will be held in New Orleans in October.