

December 16, 2013

Office of Public Health Report to the DD Council

The Title V Children with Special Healthcare Needs programs in the Office of Public Health have the mission of preventing disability and addressing the needs of children with chronic illness and/or disability and their families. They include the Genetics Program (Newborn Metabolic Testing, Lead Prevention, and Sickle Cell Disease Program), the Children's Special Health Services, Louisiana Birth Defects Monitoring Network (LBDMN), and Hearing, Speech and Vision (HSV).

Several programs have contracted with DBSysgraph through Vital Records to develop software programs that will integrate their databases with Vital Records and be web-based for improved statewide coordination, data accuracy, and data access. Integration with LEERS for LBDMN and Genetics has been completed and will be launched in the New Year. Web-based software for HSV is in the final steps of testing and revising.

Children's Special Health Services is in the final year of the Systems Integration Grant which is a three year grant that has provided funds for new activities at a time when both state and federal Title V funding were being cut. This grant has allowed CSHS to change direction as those clinics where private providers were available have been closed. More emphasis has been placed on care coordination and other services that increase access to care. These are:

- **Children's Hospital Family Resource Center:** The FRC provides community resource information to families served in Children's Hospital outpatient clinics and inpatient rehab center, no matter where they live in Louisiana. This quarter the FRC had 195 encounters and provided referral information to families on 1486 resources. They also broadcast the Baylor Chronic Illness and Disability Transition Conference to staff and physicians at Children's Hospital on October 17 and 18, to keep them abreast of latest information on helping youth with special needs transition to adulthood and maximize their independence.
- **Transportation Assistance Program:** Provided stipends to 85 families in regions 4-9 for transportation to medical appointments, when Medicaid transportation was not feasible, totaling \$13,022.

- **Care Coordination in Academic Practices:** The Statewide Care Coordinator Supervisor trained the final academic practices on care coordination for a total of 16 academic practices that have implemented the program to link families of children with special health care needs to community resources, and to make residents aware of their role in care coordination as a medical home. All of the teaching clinics for med-peds, pediatrics, and family medicine in LSU Shreveport, LSU New Orleans and Tulane medical schools have implemented the program. Practices are at different stages in integrating it into their various electronic medical records. Several practices have undergone re-organization and staff changes, largely in response to budget cuts. This has slowed the implementation process in some clinics, since some care coordinators have changed and many clinics have experienced staff shortages. Regional resource binders for participating clinics are continually updated and will continue to be when the two year care coordination contracts end. Hence, the program will continue in these clinics after the grant ends.

The care coordinator supervisor is now collaborating with Maria Blanco from the LSU School of Allied Health Human Development Center to develop lunchtime CME seminars for private practices on care coordination and the medical home, transition to adulthood for youth with special needs, and developmental screening and autism.

- **Resource Information Workshops:** A total of 110 community partners and state agency staff have attended regional Resource Information Workshops from July-November 2013. By June 2013, Families Helping Families will have conducted 81 RIW's over a three year period; 3 per year per region. The purpose of the workshops is to have public health and community program learn about each other, so that they can refer to each other in a more coordinated and appropriate manner. Pre and post-tests of participant knowledge show consistent increases in knowledge for each workshop, and also from year to year over the three years.
- **CSHS sub-specialty clinics** continue to provide access to care in regions where there is a lack of sub-specialists. 33 clinics continue in all regions of the state except Region 1. Region 1 clinics were closed in December 2010. Regions 4 and 5 (Lafayette and Lake Charles) staff were recently trained on Transition Services as part of care coordination in CSHS clinics. Training in these regions was delayed due to staff shortages. Now all CSHS subspecialty clinics are addressing transition needs of youth.

Louisiana Birth Defects Monitoring Network is in the final year of a five year CDC grant that has permitted the active birth defects surveillance program to expand statewide and to develop a web-based software system that is integrated with Vital Records. Statewide data is needed to accurately determine the incidence of various congenital conditions, since women frequently do not deliver in the parish where they live and birth defect incidence varies in different regions of the state. The program is statewide for the first time this year since hiring a final data collection specialist for the hospitals in Regions 6 (Alexandria) and 8 (Monroe) in October. Statewide data will be collected from all birthing hospitals from 2008 to present. It is expected that CDC will make similar grants available for continuation of the program when this grant ends in January 2015. The program plans to reapply.

Another component of the new software system is a referral component that will provide timely referral to health and family support resources for families of children born with congenital conditions. Specific referral information about Early Steps, CSHS Clinics, Families Helping Families, the Family Resource Center at Children's Hospital, the Early Hearing Detection and Intervention Program of HSV, and Genetics Services including statewide Genetics Clinics will be included in a computer-generated letter to each family of a child with a congenital condition detected by the surveillance system. Referrals will be age, diagnosis, and region specific. This will facilitate timely referrals and support to families trying to navigate our healthcare system to meet their infant's needs.

Genetics Program:

- The Genetics Program continues to provide newborn metabolic screening and follow-up for 28 congenital conditions via heel stick. A bill proposal has been submitted to DHH for the next legislative session that would require insurance companies to cover metabolic formula for children with metabolic conditions. OPH currently spends over \$100,000 per year on formula for families that have private insurance. Such formula is life-saving for these children and covered by insurance companies in many other states. Medicaid currently covers these formulas but private insurance usually does not.
- National Lead Prevention Week was Oct 20-26. Lead is a neurotoxin present in peeling paint, water and soil usually around old houses that can be ingested by toddlers. The program collaborated with the CDC, the US Environmental Protection Agency, and the US Department of Housing and Urban Development to organize a public health campaign to raise awareness of the importance of lead testing in the home, testing your child for lead, and learning how to prevent lead poisoning. Events included mail-outs to daycares, Head Starts, WIC centers, contractors, churches and physicians, press releases, a Program Advisory Board meeting, training for medical students and residents, contractor

trainings, trainings for WIC parents and staff and for Head Start Center directors and supervisors, a health fair in Benson Towers, New Orleans, and a walk around the Superdome lead by Secretary Kleibert. The program reports 912 people were reached during kick-off activities and trainings.

- The first Sickle Cell Commission meeting was held on October 15th in Baton Rouge. This Commission was created during the 2013 legislative session through SB 57 (Act 17) to ensure coordinated delivery of services to individuals with sickle cell disease throughout Louisiana. Sickle Cell disease can be very disabling over time, but with adequate treatment disability can be minimized and life expectancy greatly prolonged. Currently, a shortage of hematologists that treat adults with sickle cell disease, lack of adequate transportation services, lack of funding, and lack of coordination of care has led to disparate access to medical services throughout the state for this population.

Hearing, Speech and Vision ensures that babies are screened for hearing loss at birth. In LA, 99% of babies are screened, and of those with a positive screen, currently 76% are followed to ensure proper assessment for hearing loss and, when present, early intervention. Intervention by six months of age is necessary to optimize language development and later reading and school success. The 24% loss to follow-up is lower than most states, but not adequate to ensure that every child with a hearing loss receives timely intervention. The program is currently writing its MCHB continuation grant focusing on reducing loss to follow-up by working with new partners, including the OPH Parents as Teachers and Nurse/Family Partnership Home Visiting Programs, LSU HDC's Health Care Professional Training Project, Act Early statewide autism campaign and Louisiana Deaf Blind Project.