

Office of Public Health Report to the
Developmental Disabilities Council
June 2012

Children's Special Health Services: CSHS has been busy writing the annual Title V CYSHCN portion of the block grant, which is due July 14. State Implementation Grant activities continue to further our Title V objectives:

- **The Family Resource Center** is receiving more families seeking help with community referrals services for their children with special healthcare needs (CSHCN). Their first Advisory Committee meeting is scheduled for June 26th.
- **The Transportation System** with Families Helping Families is ready to expand statewide with contracts between Region 6 FHF and the other FHF offices.
- **Care Coordination in Medical Homes:** We have trained 14 academic primary care practices to date, and have funds to add 6 more practices over the next two years. Every clinic has shown tremendous improvement in their "Medical Home Index", which is a nationally recognized measure of a clinic's ability to meet medical home criteria. Targeted clinics include pediatric, family medicine, and medicine- pediatric clinics.
- **Transition:** Transition brochures and clinic checklists for helping young adults achieve independence in work, school, and health care, including securing health insurance for those aging out of Medicaid, have been widely distributed. Transition as part of Care Coordination in Medical Homes has run into some barriers in clinics with electronic medical records, which requires adding the transition checklist to the EMR. These issues are being addressed by the affected clinics.
- **Resource Information Workshops** have been a big success. Each Families Helping Families office was contracted to provide 3 RIWs during the year, for a total of 27 workshops, to help various programs and agencies that serve children with special health care needs to understand each other's programs, and to refer to each other more appropriately. Each participating program provided a 10 minute overview of their own program for each workshop. Pre and post tests were completed by all attendees to determine how knowledge increased. Year 1 evaluation results will be shared with FHF Directors and stakeholders in a meeting on July 9. Each region will conduct 3 more workshops per year for each of the next two grant years. In this way, all regional program staff that interface with families from each program should be able to attend at least one workshop per year.
- **Quality Improvement Trainings:** CSHS has assembled a group of stakeholders involved in the above grant activities to participate in Quality Improvement Trainings conducted by the Maternal Child Health Bureau State Implementation Staff. There are 3 virtual training sessions, where participants meet together and connect as a group via webinar, to participate. By this means, we are all learning about the "Plan Do Study Act" method of QI so that we can speak the same QI language.

Bayou Health: Now that Bayou Health has been rolled out throughout the state, our clinics are working to learn new procedures to make sure our children with special health care needs get all of the services, medications, DME, and referrals that they need. OPH administration is working with Medicaid to resolve some of these concerns and to try to clarify procedures for billing the new plans.

Genetics Program: One of the programs within the Genetics Program is the state's lead program. Lead is a neurotoxin that can cause neurologic and learning problems in children, and this is the program responsible for tracking children with high lead levels and making sure that lead is removed from their environments. The Healthy Homes Grant from CDC for lead abatement ends in August, and consequently the State Lead Program has been forced to end its contract with the City of New Orleans that supports its lead program. However, the program was successful in obtaining a \$50,000 grant from the Environmental Protection Agency that will permit the core activities of the state program to continue. The program is also supported by State General Fund dollars. The blood level that is considered toxic to children has recently been decreased by CDC from 10µg/dl to 5µg/dl.

Currently the Genetics Program screens newborns for 28 conditions. Recently there has been interest in adding Critical Congenital Heart Disease to these conditions by requiring every newborn to have a pulse ox to detect cyanotic heart disease. This is currently being studied by LA but if added, would not be added until at the soonest, the next legislative session.

Hearing, Speech and Vision: HSV is ready to contract with DBSysgraph for development of a web-based software system that will integrate with the Louisiana Electronic Event Recording System (LEERS), which is their interface with vital records. This is how the program ensures that all children born in Louisiana are screened for hearing. This is significant because until now the program has used an ACCESS database that cannot be accessed by internet from different points around the state. This will permit the various regional staff to access the database and reports from wherever they are. The program has identified funds in their CDC grant to support the database development.

This is also significant because our other programs including LBDMN and Genetics will be developing LEERS modules. This will permit all of the programs using LEERS to share and integrate data for all the babies born in the state. For example, an infant with a syndrome involving hearing loss or a metabolic condition who is identified in the LBDMN could be tracked to see if they receive services in the HSV program or the genetics clinics, and then perhaps in the Early Steps program. This integration could be used to make sure families are aware of services their child might benefit from, and it could be used to help programs track children to make sure they don't fall through the cracks. We are still negotiating for this and are hoping to have all of this work completed within the next two years.

Louisiana Birth Defects Monitoring Network: LBDMN is working with CDC to obtain carry-over funds from the first year of their 5 year CDC grant (now in year 3) for development of its LEERS module and web-based database. This would provide \$122,000 for software development, which was one of the main goals of the grant.

LBDMN has recently hired two new data collection specialists (DCSs) for Regions 1 and 3. This leaves Regions 5, 6, and 8 still uncovered; the program is hoping to combine the work for Regions 6 and 8 to provide full time employment for this DCS and to make it easier to obtain statewide coverage.

The program is focusing on developing training modules for its DCSs and on community outreach and education to prevent birth defects. As such they are involved in several community events, including the Spina Bifida of Greater New Orleans 2nd annual Parent/Young Adult Conference, the 27th Annual Camp Friendship, and the Ruston Community Health Fair. All are scheduled for this July. The Data Collection Specialist Supervisor, who is the parent of an adult with spina bifida, is also serving as a parent facilitator for the Family Resource Center Advisory Board.