

## **Office of Public Health Report to the Developmental Disabilities Council**

**June 2013**

**BUDGET!!** The Title V CYSHCN Programs were targeted for a \$794,000 cut in the Governor's budget, including 8 T.O. of staff working in Children's Special Health Services regional subspecialty clinics. In May, at the request of the DD Council, the Title V CYSHCN Programs Director presented a budget reduction plan to stakeholders during two meetings, one in Lafayette and one in Baton Rouge. Stakeholders, including DD Council members, were successful in getting both the House and the Senate to restore this money to H.B.1, only to be vetoed by the Governor. The Office of Public Health is working to absorb this cut with the least impact to services possible. In addition, OPH has asked CSHS to make additional cuts to contracts.

As of this writing, it appears that 3 of the eight T.O. will be taken. Other savings will come from contracts that were cut in 2013 from clinic closures and in retirement savings from people who retired in 2013. Additional clinic closures will be minimized. Additional contract cuts include elimination of two vision screening contracts and decreases in hospital contracts. The vision contracts provided for vision screening of young children in daycares and teaching vision screening to school nurses and volunteers. This program was targeted because this is not a mandated activity, and physicians screen for vision during well-child visits. Hospital contracts were decreased because they are generally not fully expended. They are in place to cover medical expenses for children without any health insurance, and currently, all but 3% of CYSHCN in LA have health insurance. Hospital contracts will remain in place, but at minimal amounts, to provide a safety-net for these children. OPH is still determining final contract cuts to the 2014 Title V CYSHCN budget.

**Database News:** The development of the LA Electronic Event Registration System (LEERS) modules for integration of a web-based database with vital records is complete for Louisiana Birth Defects Monitoring Network (LBDMN) and Genetics Programs, and is expected to be complete for the Newborn Hearing Screening Program in the third week of July. The new application for the Genetics Program has been tested successfully and is waiting for publication of the application for program use. The new application for LBDMN is waiting for DHH IT to provide a data server for testing. This has been delayed due to IT staff shortages. Once testing is complete, the final software will be ready for program incorporation.

**Children's Special Health Services:**

*Family Resource Center (FRC)* –The FRC continues to provide community based resource information to clients: March-May 2013: 380--total client encounters; 2,065--resources provided.

The FRC Youth Liaison (YL), Steven Nguyen, is working with Rehab directors at Children's Hospital to plan an annual event for former rehab clients that would provide information about recreational activities and summer camp. This annual program would also include a visit to a Miracle League game. Children's Hospital's magazine publication, *Small World*, had a feature article on Steven and his AMCHP scholarship and visit to Capitol Hill with Mary Landrieu and David Vitter, featuring his picture on the cover!

The FRC will begin providing services in Neurology Botox & Spasticity clinics. The FRC provided 300 Recreation Resource Guides for the Gulf South, 228 Families Helping Families statewide flyers, and 138 FRC brochures to families via information tables in the CHNOLA main and ACC lobbies.

The FRC continues to maintain its Advisory Board. Elizabeth Heideman, a Tulane college honor student and amputee, was hired as Youth Facilitator for the Advisory Board. The next Advisory Board meeting will be held in July.

FRC staff continue to participate on local and CHNOLA boards and committees. The parent liaison participates on the CHNOLA Commission on Accreditation of Rehabilitation Facilities (CARF) Outcomes committee to provide family input. She also attends Rehab department meetings. FRC staff remain abreast of best practices by participating in trainings and webinars. Webinars/trainings attended this quarter include: Got Transition Webinar: Health Care During an Emergency in an Unfamiliar Setting, Hot Topics in La Healthcare, La Family to Family Center's Leadership Academy, CSHS PL/YL Training in Alexandria, Scott Chesney (Christopher Reeve Foundation) program at CHNOLA.

*Transportation Assistance Program* - During this quarter, funds were exhausted for this activity with CSHS assisting 12 families with transportation assistance to medical appointments/medically necessary services. This quarter's disbursements totaled \$ 3,346.70. Assistance will resume July 1, 2013 when new funds are available.

*Medical Home—Care Coordination (CC) and Transition-*  
CSHS begins its third and final year of implementing care coordination in academic practices July 1. Contracts for three new practices were routed to begin this summer:

- Tulane Lakeside Pediatric Continuity Clinics
- LSU Louisa Street Pediatric Clinic

- LSU SW Louisiana Family Medicine Clinic

This makes a total of 19 practices with Care Coordination implementation, 15 of which have been academic practices.

The Statewide CC Supervisor continued to provide updated resource materials to practices that have had prior CC contracts and provide didactic information on the medical home for LSU and Tulane pediatric residents completing their development rotation. As the implementation of care coordination in academic teaching practices winds down, she is preparing to work with private medical homes (pediatric and family medicine offices) to implement “lunch and learn” sessions on medical home and care coordination, transition services for youth with special health care needs, and screening and referral for children with suspected autism spectrum disorders (ASDs). She is applying for continuing education credits for participants in these activities. Selected resource materials for families of CYSHCN have been mailed to over 500 providers.

*Resource Information Workshops (RIWs)* – Grant year 2 RIWs continue across the state to help agencies/programs that serve CYSHCN learn about each other. By June 30<sup>th</sup>, each Families Helping Families will have completed 3 RIWs in each DHH region for a total of 27 RIWs in Year 2 and 54 RIWs total for the first two years of the grant. A Year 2 Mid-Year Review Webinar was held April 12<sup>th</sup> to provide technical assistance to FHF Directors on protocol adherence related to the pre and post knowledge assessment. The annual RIW follow-up meeting is scheduled for Thursday, July 11<sup>th</sup> in Baton Rouge. During that time, change in knowledge results stratified by program and by region will be presented by the CSHS Epidemiologist. Program managers from each of the 7 state agencies participating in RIWs, as well as FHF staff who coordinate and conduct RIWs have been invited to attend. The final year of the grant begins in July 2013. The final 27 RIWs are planned.

**Hearing, Speech and Vision:** The HSV program continues its activities of newborn hearing screening and intervention and audiology and speech clinics including provision of hearing aids. As noted above, the vision screening in daycares and vision screening training of school nurses and volunteers will end in July 2013 due to budget cuts. In May, Hands and Voices held its first fund raiser at Rock & Bowl for the new “Guide by Your Side” program, which pairs experienced parents of children with hearing loss with parents of newly diagnosed children. The event included bowling, food, and a silent auction of donated prizes. The event was a tremendous success and was attended by over 200 participants and raised over \$5000 for the organization. **H & V** hopes to use the money for future activities and educational events and the possible addition of another Parent Guide. Currently Parent Guides are trained by the national organization and paid through one of LA EHDI’s federal grants.

**Louisiana Birth Defects Monitoring Network,** LA’s active birth defects surveillance system will be state wide in 2014 with the hiring of one more data collection specialist. This position will be funded by restoration of federal sequestration cuts.

Act 307 (formerly House Bill 322) requires all newborns to have pulse oximetry prior to hospital discharge to rule out cyanotic heart disease. This is a simple screening that could potentially save lives. Infants with a positive screen will need pediatric cardiology evaluation and if indicated, an echocardiogram. In hospitals that do not have a pediatric cardiologist available, the infant will need to be transferred to another hospital for evaluation. The Act will certainly assist in more timely diagnosis of Critical Congenital Heart Disease diagnosis, which will be captured by the birth defects surveillance system. However, OPH will not be responsible for oversight of this activity, which would have been very difficult for the LBDMN program to provide within its current budget. This was left to hospitals to implement.

Act 184 was also signed into law, which keeps the LBDMN Advisory Group intact and separate from the Perinatal Commission. Thus, the current Advisory Group will remain active and unchanged.

The Family Resource Guide has been updated and can be accessed at the LBDMN website: [www.dhh.la.gov/LBDMN](http://www.dhh.la.gov/LBDMN). This is a booklet for parents of infants with birth defects, designed to help them begin to navigate the healthcare resources they may need. A flyer has been printed directing families to the Resource Guide, which will be widely distributed by the program to birthing hospitals and collaborating programs.

The 2005-2008 LBDMN data has been submitted to our partners in the Louisiana Environmental Public Health Tracking Network (LEPHT) to link birth defect prevalence rates with environmental hazard or exposure data via geomapping. These analyses will provide important information for public health officials and researchers. Security testing, production review, and deployment of the query-able EPHT portal occurred in May 2013. Data tables should be complete by July 2014, although regional data will not be published online due to incomplete data that could lead to misinterpretation.

### **Genetics Program:**

Act 117 passed by the La legislature requires OPH to work with Sickle Cell Foundations, Medical Providers and Medicaid to establish a Louisiana Sickle Cell Commission with the goal of ensuring care for patients with SS Disease throughout Louisiana.. The program is in the process of meeting with collaborators to develop the list of commission members in accordance with the new statute.

Trina Evans, MPH began as the new program monitor for the Childhood Lead and Healthy Homes program. Trina has extensive experience in public health as State Adolescent Health Coordinator of the Louisiana Adolescent Health Initiative, State Women's Health Liaison to the federal Office on Women's Health, State Project Director of the DHH-OMH-Louisiana Partnership for Youth Suicide Prevention, and as Program Monitor of the Louisiana Adolescent School Health Program. Trina brings some wonderful management and grant writing expertise as the program seeks to obtain new grants after the 2012 loss of CDC grant funding for the program.