

Title V Children with Special Health Care Needs Programs
March 2012

As of February 6, **the Genetics Program** has been moved under the umbrella of the Title V Children with Special Health Care Needs Programs, along with Children's Special Health Services, Hearing Speech and Vision, and Louisiana Birth Defects Monitoring Network. This is appropriate because it is the only other program within the Office of Public Health that is entitled to receive funds from the one third of the MCH Block Grant designated specifically for Children with Special Healthcare Needs. **The Genetics Program** includes programs that address **Newborn Metabolic Screening and follow-up, Regional Genetics Clinics, Sickle Cell Anemia, Thalassemia, Hemophilia, and Lead Prevention**. The Program Manager will continue to be Cheryl Harris.

This consolidation was done to streamline operations between the two programs as well as to provide medical direction for the program. Two state positions were cut in the consolidation: an Administrative Program Specialist A and an Administrative Coordinator IV. The Genetics Program and the Children's Special Health Services Program have many things in common: both contract with subspecialty physicians to provide direct services, and already share many regional clinic staff. Because they have developed independently under separate funding and legislation, there are some key differences between the two programs. Genetics has no income eligibility limitations, and CSHS does. It also has no age limits, which means that it serves many adults who are uninsured, whereas over 95% of the children served in CSHS have some form of health insurance.

Children's Special Health Services: Progress continues on our State Implementation Grant activities:

- The **Family Resource Center (FRC)** at Children's Hospital is open and accepting referrals from all Ambulatory Care Center clinics to meet with families, conduct a brief needs assessment, and link families with needed support services for their children with special needs. The FRC is actively conducting daily outreach to clinics, physicians, and hospital staff to increase awareness of its services.
- **Regional Information Workshops (RIWs)** for public health staff are being conducted through contracts with Families Helping Families in every region. The purpose of the RIWs is to familiarize public health staff with each other's programs to improve referral and coordination between programs. Each region has contracted to conduct 3 workshops throughout the year, so that different program staff from each program can attend. So far, RIWs have been very well attended, have received excellent reviews, and have been attended by representatives outside of DHH and DCFS, such as Senator Jon Johnson's office.

- **Transportation Services** including stipends for families in Region 6 to attend medical appointments and actual transportation when needed are now available. To date, about 10 families have received stipends. Beginning in July, contracts with the other regional FHF offices will be made available to make this service available statewide. Surprisingly, many families have indicated that new Medicaid transportation services are now available in Region 6 via “Medicab”. Stipends are only available to families with no other means of transportation, so if Medicab services are available, stipends are not offered. So far, families using Medicab services appear to be pleased. Families receiving stipends to help meet their own transportation expenses have also reported complete satisfaction.
- **Care Coordination** in primary care offices continues to expand. A full time care coordinator was recently selected for the LSU-Children’s Hospital Tigercare Pediatric Clinics in Kenner and Prytanis locations. Contracts for care coordination training have also begun with the LSU Family Medicine Clinic in Kenner, the LSU Pediatric Clinic in Shreveport, and the Tulane Med-Peds Clinic in New Orleans. A focus on youth with special needs and transition services has been incorporated into care coordination in all clinics.
Unfortunately, two of the clinics that were very successful medical homes with care coordination contracts were recently closed due to LSU budget cuts, including Earl K Long and University Medical Center Pediatric Clinic in Lafayette. The Earl K Long practice was that of Stewart Gordon, immediate past president of the LA AAP chapter, and one of the largest most comprehensive medical homes in the state. We supported a social worker and a part time OT who provided care coordination, and who devised a data software system that we used for care coordination in other clinics. The loss of these two care coordinators as well as access to their software system is a huge loss for us. Attempts to transition these contracts to OLOL have not been successful.
- **Care Coordination Training focusing on Youth in Transition in CSHS clinics** continues, with training for Region 2 on March 20 and training for Region 9 on April 23rd. The only remaining regions to be trained are Regions 4 and 5, which should be completed by the end of 2012. At that point, expanded transition services will be available in all CSHS clinics.

Louisiana Birth Defects Monitoring Network: This is an active surveillance program to determine the number and types of major birth defects in Louisiana. To date, the program has only maintained coverage of approximately 80% of birthing hospitals, and has had delays in establishing a web-based software system with linkage to vital records because of delays in transferring a software system from CDC. To resolve these issues, a revised strategy has been enacted to increase the pay of data collection specialists, combine positions in Regions 4 and 6, and use grant carry-over funds to contract for web-based software development and linkage to vital records. With this new plan, the surveillance system should have 100% state coverage and be web-based and linked to vital records by the end of its current CDC grant in 2014.

Hearing, Speech and Vision:

NICHQ recently recognized the LA team as a “Success Story” for this year. The EHDI team was interviewed and recognized in the NICHQ newsletter, in a video on the NICHQ website, in training packets, and at their April national learning collaborative session.

The HSV Program staff recently attended the National Early Hearing Detection and Intervention (EHDI) Conference in St. Louis. Dr. Thiravat Choojitarom, a pediatrician from Denham Springs and the LA State Chapter Champion for EHDI, presented a statewide survey of pediatricians emphasizing the role of the medical home in the care of hearing impaired infants. The presentation received an outstanding rating and was “standing room only” in attendance.

Another recent development is the LA Chapter of “Guide by Your Side” (GBYS), which is a support organization for families of children with newly diagnosed hearing loss that provides emotional support and unbiased information from trained parent guides. GBYS is a trademarked program of Hands and Voices and available to Hands and Voices chapters.