

Children's Special Health Services
December 16, 2011

Children's Special Health Services:

Children's Special Health Services is very proud to have our long time employees receive one of the Governor's Office of Disability Affairs Outstanding Leadership in Disabilities Awards. Our Statewide Parent Training Coordinator, Esther McGee, received the 2011 Volunteer of the Year Award. Esther retires this year in March after 20 years in CSHS, teaching parents of children with disabilities how to help other parents in our CSHS subspecialty clinics. Esther also writes the Family Matters Newsletter that is distributed in all of the OPH clinics. Esther's lifetime work was inspired by her daughter Kim, who was born with many life-threatening disabilities and was not expected to live. Kim is now 34 years old. Esther has many, many volunteer accomplishments in addition to her work with CSHS. One of them was working with the Twin City Mayor's Committee in Monroe to set up a scholarship fund for youth with disabilities that now fully funds 10 students with special healthcare needs per year with college scholarships. She also leads a parent support group for parents with children sharing Kim's medical issues, which is now 20 years old.

Our Family Resource Center (FRC) at Children's Hospital in New Orleans is taking shape. Our old office space has been completely renovated and the FRC will officially open with its new look in January. For those of you in Region 1 who have reason to visit Children's Hospital, I encourage you to go to Room 2020 and say hello and take a look. The FRC will provide parent support and care coordination for families of CYSHCN attending selected sub-specialty clinics at Children's. We are working with Children's Hospital administration to coordinate referrals. The FRC will be hiring both a second parent liaison, as well as a youth with special healthcare needs to help primarily with transition issues of other youth to adulthood. The FRC may serve as a pilot for future resource centers in hospitals in urban areas of the state where care coordination is a pressing need.

FHF in Alexandria has begun the new transportation stipend system for families in Region 6. Families of CYSHCN who meet financial criteria (ie have Medicaid) and medical criteria (ie have a medical diagnosis that qualifies them for one of our clinics) may apply for help with transportation to medical appointments. The needed transportation must not be available through Medicaid. CSHS will provide stipends to help offset travel costs and actual van transportation if needed to help families keep medical appointments. This will be expanded the second year of our grant to other FHF interested in participating.

The first Regional Information Workshop to help various agencies and programs that serve CYSHCN refer more appropriately to each other was held in Shreveport in October. About 40 people attended from various public health agencies and programs that serve CYSHCN. Each program that serves CYSHCN described their program eligibility requirements and how to refer potential clients. The goal is to improve coordination of public health and community services for families of CYSHCN.

Our transition training for CSHS clinic staff in Shreveport and Monroe in October went well. We have now implemented the new system in Regions 1, 3, 6, 7 and 8, with 4 more to complete the training by the end of 2012.

The 2010 National Survey of CYSHCN results were just released. This is a large telephone survey conducted by CDC to determine how well states are meeting the 6 National Performance Measures (NPMs) that center around Medical Home. The survey has been conducted 3 times: 2001, 2006, and 2010. In 2001 we were below the National Average in everything. In 2006, immediately after Katrina, we were above the National Average in 4 out of 6. The only areas we lagged behind in were newborn screening, which was due to Hurricane Katrina and the fact that the system was nonfunctioning for several months, and transition to adulthood, which was a problem for all states. After Katrina many of our most complex, neediest patients had left the state. In the most recent survey, many of those patients had returned. The % CYSHCN in LA increased from 14.8% to 18.6%. In the most current survey, the only 2 areas where we are above the national average are insurance coverage and access to community based services. In four areas we are below the national average: families partner in decision making, families receive coordinated, ongoing care in a medical home, newborn screening, and transition to adulthood. Hopefully, implementation of Bayou Health and the CCN's will improve these NPM's by improving outreach for enrollment, improving access and care coordination by physicians and renewing medical home linkages.

Finally, we received our Title V 2012 Block Grant review written report. MCHB reviewers were impressed with how we address specific NPM's and with our family involvement at all program levels (state, local and individual). Concerns were related to the state Title V reductions in spending, the Medicaid deficit, and our ability to continue to provide safety net services in a depressed economy where there is increased need for them. They recommended that the state ensure continuation of our care coordination and Medical Home activities, which, currently, are covered by a 100% MCHB federal grant that does not require a state match. There were no requirements.

Louisiana Birth Defects Monitoring Network

January is National Birth Defects Prevention Month. LBDMN is working with the CDC, March of Dimes and community agencies to distribute pamphlets about congenital heart disease, folic acid, substance abuse and medications in pregnancy.

The program has been trying to hire data collection specialists for Regions 1, 3 and 5. These are the people who go into the hospital medical records departments to abstract the information on babies born with birth defects. Surveillance data cannot be statewide unless all DCS positions are filled in all regions. Since many are part-time, these positions are pretty high turnover. A DCS has been selected for Region 1 and a temporary DCS has been selected for Region 3. But, the half time positions in Region 3 and Region 5 both remain unfilled at this time.

The program is currently using an ACCESS database which is available to regional DCS as well as DHH SharePoint, and hopes to move to a web-based CDC software program on a SQL server as soon as it is available from the CDC.

Hearing, Speech and Vision

HSV Early Hearing Detection and Intervention (EHDI) staff and the Advisory Council for EHDI have been working with the AAP Chapter Champion for Newborn Hearing Screening, Dr. Thiravat Choojitarom, a pediatrician from Denham Springs, on an online survey of pediatricians to determine their knowledge of newborn hearing screening protocols. Data from the survey will be presented at the National EHDI Conference in St. Louis in March. Current recommendations are that all infants are screened by one month, receive audiology assessment by 3 months, and intervention by 6 months in order to optimize speech, language, and school outcomes for children with hearing loss. Pediatricians must understand these guidelines if they are to implement them successfully.

The EHDI program has teamed up with WIC to distribute brochures in English and Spanish to expectant mothers attending WIC clinics, to educate them on their infant's hospital hearing screening and the importance of any recommended follow-up. Posters have also been provided, as well as education of nutritionists and nurses participating in WIC. The awareness campaign has begun in Regions 1, 2 and 4.