

Report to the Developmental Disabilities Council
March 24, 2008

Children's Special Health Services held its annual Statewide Parent Liaison Training on March 11 in Lake Charles. The training was led by our State Parent Consultant Angie Myers and our CSHS State Parent Coordinator, Esther McGee. Nine parent liaisons attended from all regions of the state and were trained in our new Care Coordination Program. Lisa Williams from The Advocacy Center also spoke about Housing Rights, Registering to Vote, and Voting Issues for Persons with Disabilities. Our Parent Liaisons are all parents of children with disabilities who are contracted through Families Helping Families to work in our CSHS subspecialty clinics. They provide support to families coming to our clinics and help link families with community resources.

CSHS has two model medical homes (pediatric clinics) where we sponsor care coordinators. One of these is Tigercare Pediatric Clinic on Canal Street. This is a Children's Hospital Pediatric Clinic where LSU pediatric residents receive much of their outpatient training. CSHS contracts with Children's Hospital to put a care coordinator in the clinic to help link families of children with special health care needs with various community services and resources, which is an important part of the medical home concept for primary care.

Our care coordinator conducted surveys of the staff and the families coming to the clinic before and after care coordination in the clinic to determine the effect of the care coordinator in meeting "Medical Home" Criteria and on family satisfaction for families of Children with Special Healthcare Need (CSHCN). The surveys demonstrated that the care coordinator did improve the ability of the clinic to meet medical home criteria, and resulted in a tremendous improvement in family satisfaction for families of CSHCN. This data was presented to the Louisiana Health Care Quality Forum and will be presented again at the Medical Home Summit that the LHCQF will host in Baton Rouge on May 23. This is a statewide summit that will bring in several national experts to help promote the medical home model in Louisiana. Our long range plan is to increase the number of care coordinators in key pediatric practices in the state.

Our CSHS Care Coordination pilot is finally ready to be launched in Alexandria at the end of April. CSHS has always done Care Coordination in its clinics, but this is a more systematic, more comprehensive way of assessing family needs and making a plan to meet those needs. It is web-based, so that if children in healthcare shortage areas have to travel to another region for sub-specialty care, their care coordination plan will be able to be assessed by that region. Initially, we will only offer this to teens age 14 and above to target their needs for transitioning to adult services. There have been many delays post-Katrina in getting this off the ground, mostly related to revision of the database to make it web-based, but by the next DD Council meeting I should be able to give a report of how the pilot went. Over the next two years we hope to roll this out statewide.

Our Birth Defects Monitoring System is mandated to be a statewide program, capturing all births in the state and providing resources to parents of infants detected by

the surveillance system. This program was legislated in 2001 but without state funding, and therefore it has not been able to provide statewide coverage. This year the program did receive some state funding for expansion and was able to hire a second program monitor, Dionka Pierce, who started January 7. She has already drafted a booklet of resource information for families that is still undergoing final revisions before it will be mailed to families of children with birth defects. The program is currently active in Regions I, II, V and VII and is currently expanding to region IX and next month will expand to region IV. With adequate state funding, the program would be able to expand to 100% of births within a couple of years. When 100% of births are covered, we will be able to generate statewide rates of specific birth defects.

Hearing, Speech and Vision provides for universal newborn hearing screening and follow up with the goal of getting infants with hearing loss into early intervention by six months of age, so that optimal language and reading outcomes can be attained. The 2008 National Early Hearing, Detection, and Intervention Conference for newborn hearing screening was held in New Orleans in February, attracting over 500 professionals from across the US. We were pleased to be able to be the host city for this important conference. After the conference, 50 attendees stayed and volunteered with Habitat for Humanity to help rebuild homes in the Musicians Village.

Hearing, Speech and Vision provides hearing aids to CSHS eligible children. In 2007, 328 hearing aids were issued.

Hearing Speech and Vision also contracts with two vision screening specialists to train school personnel to provide vision screening. In 2007 over 780 professionals and volunteers were trained, and over 16,000 preschool children received the Photo-screener vision screening from volunteers trained by one of the vision specialists.