

Children's Special Health Services
Report to the Developmental Disabilities Council
March 2009

Staffing: CSHS recently hired a **new program manager, Dionka Pierce**. Dionka replaces Laurent Lebien who left in December. Dionka came to us about a year ago from MCH epidemiology, where she coordinated the LaPRAMS program. This past year she has been working with CSHS in the Louisiana Birth Defects Monitoring Network program as a Family Resources Coordinator, where she developed the resource guide for parents of infants in the registry. We are very pleased to have Dionka promoted to this position.

CSHS also recently hired a **statewide care coordinator supervisor, Arleen Williams, RN**. Arleen has already begun to develop resource materials for private pediatricians. She will supervise care coordinators that are placed in pediatric practices and help them implement the system we developed at the Tigercare Clinic, which was so successful at improving the satisfaction surveys of families with CSHCN coming to the clinic.

In spite of the hiring freeze, we have been granted permission to fill both the Family Resources Coordinator position and our CSHS social worker position, which was vacated by Maxine Kimbrell in February. We have many applicants for the social worker position and will begin interviews this week.

2010 Budget Cuts: CSHS anticipates a \$500,000 cut to its 2010 budget. We are somewhat protected from this cut by a policy change we made earlier this year regarding young adults with cystic fibrosis. In the past, we have continued to cover this population even after they aged out of our system at age 21. However, in December 2007 we met with Medicaid and SSI disability to find out why our patients were being denied SSI Disability coverage, and to learn about other health insurance options that they may qualify for. With the help of Medicaid and SSI, we were able to work with our social workers in the regions to get most of our adults over age 21 on either SSI Disability or the Medicaid Purchase Plan. We found comprehensive coverage for all but five of the young adults we were serving, which dramatically decreased our pharmacy costs, which average about \$8,000 per month for a patient with CF. We continue to work with the five young adults without insurance. When a young adult has full coverage and does not need us any more, they are discharged from our services. They can still come to either of our CF Clinics, but we are no longer providing their health coverage. This has dramatically decreased our pharmacy expenditures, which has helped us to absorb the cuts without hurting us and actually helping the population we serve.

CSHS Program Activities: CSHS completed a four day training on Care Coordination in Region 6 (Alexandria), which was well received. We are working with CSHS staff on an ongoing basis to help them become efficient in the new process. Training has now occurred in regions I (Orleans) and VI. Implementation is a little slower than we had hoped but with practice we think the system will assist the regions greatly in meeting the needs of families. Next we plan to target Region IV (Lafayette).

We are also planning our **2010 Needs Assessment** which is required by our Title V MCH Block Grant every 5 years. We are beginning the planning now which will involve summarizing known data regarding CSHCN, forming a stakeholder group to assist with gathering relevant data that is missing, and possibly surveying a sample of pediatricians and family practitioners to determine how much care coordination they are actually doing in their practices. This information will be used by our new care coordinator

supervisor as she further develops and implements our Medical Home intervention in pediatric practices. The Needs Assessment will be due to MCHB in Spring of 2010.

Our **Birth Defects Monitoring Network** is waiting to fill the Family Resource Coordinator position vacated by Dionka. There are only two positions in central office to run this entire statewide program along with the data collection specialists in each region. We are still waiting for that position to be posted. In 2010 we plan to hire an epidemiologist and two more data collection specialists in order to bring our birth coverage to 100%.

The first analysis of our LBDMN data from 2005 was presented at the National Birth Defects Prevention Network annual meeting, and is being prepared for submission for publication.

The LBDMN website page has been updated with a new home page, "About LBDMN" and "Family Resources" pages.

Our **Hearing Speech and Vision Program** provided 717 audiology/ speech visits , 211 hearing aids, and 569 speech/language screenings for infants and toddlers in 2008. It facilitated screening of over 97% of newborns in the state for hearing loss at birth. It successfully followed 64% of infants with positive screens for hearing loss through confirmation and early intervention, which is considerably greater than the average for other states. Over 1063 professionals and volunteers in schools and pre-schools were trained to conduct vision screenings in 2008. The program is working with DHH IT on a web-based newborn hearing screening database to facilitate follow-up of infants throughout the state. The program is limited by having only 3 audiologists serving all 9 regions of the states, which has the potential to limit access to audiology services for many children.