

Children's Special Health Services
September 26, 2011

OPH: Secretary Greenstein announced that Clayton Williams, the Assistant Secretary for OPH, will leave on October 14 after two years at DHH. Secretary Greenstein will undergo a national search to find a replacement. In the meantime, JT Lane, his Chief of Staff, will serve as Interim Assistant Secretary. JT joined DHH in 2008 as Deputy Chief of Staff overseeing the Bureau of Media and Communications and special projects and initiatives, including taking leadership roles in the Making Medicaid Better initiative and the oil spill response.

Courtney Phillips will fill in as Interim Chief of Staff. Courtney came from Medicaid where she had many roles, including the project coordinator for the My Place demonstration project (Money Follows the Person Grant). We are assuming that Beth Scalco will remain in the position of Deputy Assistant Secretary.

Children's Special Health Services:

CSHS has finally had a chance to focus on our new grant activities rather than budget cuts, although we have been told that more cuts are on the way. OPH has to absorb \$10 mil in cuts this year, and some will most likely come from CSHS central office staff cuts, but none of them have been finalized yet.

Contracts have been initiated for our transportation grant with FHF to provide stipends to families for medical appointments, for expansion of our Family Resource Center at Children's Hospital in New Orleans with a nurse supervisor and youth with a special needs to assist other youth, and for FHF to provide Regional Information Workshops to help staff learn more about eligibility criteria for public health programs serving Children with Special Healthcare Needs. Front-line regional staff from the following programs will be invited to participate:

1. Early Steps
2. Department of Children and Family Services (DCFS) Child Welfare Division, Child Protection Investigation -Family Services section
3. DCFS-Child Development and Early Learning Division, Head Start Collaboration Project
4. Children's Special Health Services
5. Office for Citizens with Developmental Disabilities-SPOE offices
6. Louisiana Rehabilitation Services

Care coordination training in Transition Services for Youth with Special Healthcare Needs will expand to Regions 7 and 8 (Shreveport and Monroe) on October 17. CSHS subspecialty clinics are already offering Transition Services in Regions 3 and 6 (Thibodeaux and Alexandria). Four of our staff will be attending the 12th Chronic Illness and Disability Conference on Transition from Pediatric to Adult-based Care in Houston, Texas on October 19-21 to learn more about what other states are doing and what the

latest research in transition has shown to be effective. This is a collaborative effort of Baylor College of Medicine, Texas Children's Hospital, and the MCHB sponsored Leadership Education in Adolescent Health (LEAH) Training Program.

Our Title V Block Grant review took place on August 17. It went very well with no corrections or revisions. We usually get the final report sometime in November.

Hearing, Speech and Vision (HSV): The HSV program is currently working with DHH to update the HSV/Early Hearing Detection and Intervention (EHDI) website with links to national references for parents, professionals and shareholders. All developed policy guidelines are also now on the web site for healthcare providers (physicians, audiologists, etc.) for easy access.

HSV continues to participate in the MCHB and partner National Initiative for Children's Healthcare Quality (NICHQ) 12 month learning collaborative to address follow up after newborn hearing screening, including diagnosis and referral into early intervention. Staff also continue to participate in the Early Childhood Hearing Outreach (ECHO) Initiative, an outreach of the National Center for Hearing Assessment and Management (NCHAM) at Utah State University. The ECHO Initiative focuses on extending the benefit of periodic hearing screening to children 0 – 3 years of age in a variety of health and education settings. HSV staff have partnered with ECHO, NCHAM, and two Early Head Starts in Louisiana to pilot/develop systems of hearing screening in the Early Head Start environment.

Louisiana Birth Defects Monitoring Network: LBDMN has submitted its first National Birth Defects Prevention Network Surveillance Report to CDC for birth cohorts 2005, 2006 and 2007 combined. The program was not statewide during these years, so prevalence rates in the report are more valuable for surveillance of areas captured or qualitative information than for accurate statewide disease specific rates.

The program conducts active surveillance of all birthing hospitals, but continues to monitor for birth defects until age 3. Defects that are not detected at birth may not yet be captured by the surveillance system, since surveillance of subspecialty clinics is just beginning. Recent progress includes:

Surveillance: The program converted 3,456 records from paper forms to searchable scanned data images, partnered with Environmental Public Health Tracking to improve data quality and begin GIS mapping of defects to detect possible associations with environmental toxins, and has taken steps to support electronic data collection including a new electronic abstraction form and modified software.

Referral to Services: The program has updated its website and added the updated Family Resource Guide to the website for use by families.

Prevention: LBDMN has strengthened its partnerships with Hearing, Speech and Vision, MCH epidemiology, Genetics, Family Planning, and Vital Records. The program has always enjoyed collaboration with the March of Dimes. LBDMN continues to look for opportunities for data sharing and integration to aid in the detection, referral to services, and tracking of children with birth defects. January is Birth Defects Prevention Month, and LBDMN is already planning to focus on defects of the heart, which are our most common birth defect in Louisiana. More on that to come!