Office of Public Health Report to the Developmental Disability Council September 20, 2012

Office of Public Health: Title V Children and Youth with Special Health Needs

Title V CYSHCN Programs now include Children's Special Health Services, Genetics, Hearing Speech and Vision, and the Louisiana Birth Defects Monitoring System. Title V programs had their annual MCH Block Grant Review at HRSA in Dallas on August 24. The review went well; we will get out final report in November. Legislature fact sheets have been developed for each of the Title V CYSHCN programs, which are available upon request.

Children's Special Health Services:

The Family Resource Center at Children's Hospital, New Orleans continues to increase its presence at Children's Hospital. From August 16-September 16 they had 112 encounters and made 332 referrals, despite being closed 4 days for Hurricane Isaac. Their brochures are now placed in the Ambulatory Care Clinic suites, Physical Therapy, Occupational Therapy, and Speech Therapy departments, Dental Clinic, and Orthotics and Prosthetics vendor area. On August 17 they made a presentation to the nursing staff and they are waiting for a date to talk with the genetics staff. On September 10 they hired Stephen Nguyen as the Youth Liaison. He will train with our Parent Liaisons, who participate in extensive training throughout the year for both clinic parent liaisons and Early Steps family service coordinators, conducted by Angie Myers and Cathy Dove. The FRC was invited to participate in the CHNOLA Rehab Reunion on September 12. Thuy Nguyen, a Parent Liaison, has been asked to serve on several committees for Children's Hospital including attending the CHNOLA Rehab Planning Meeting. The next FRC Advisory Council meeting is scheduled for November 15, 2012.

The FRC works closely with FHF to refer children from around the state using Children's Hospital Clinic services to the FHF office nearest them.

The Transportation System providing transportation stipends for CYSHCN and their families has expanded from Region 6 to Regions 7 and 8. Contracts were offered to Families Helping Families offices in each region, but to date only Regions 7 and 8 are using them. Utilization was as follows: July 9 families, August 7 families, and September 10 families for a total of 26 families assisted this quarter. All regions agreed to the contracts, so it is unclear why the other regions have not identified families who need them. It is the CSHS nurses and social workers that identify most families in CSHS clinics, although families identified through FHF that meet CSHS eligibility criteria are also eligible. The CSHS Program Manager will be contacting these regions to

identify reasons for under-utilization. We are hoping that it is because of adequate Medicaid transportation or adequate medical providers in the regions. Stipends are only available to families when the family has no means of transportation and Medicaid transportation is not available, which is frequently the case when a child has an appointment in another region such as New Orleans or Shreveport.

Care Coordination in Medical Homes: CSHS has continued to help academic primary care practices identify care coordinators and provide training and materials for them, to increase the medical home capacity in our state. Be choosing academic practices, all of the pediatric, family medicine and med-peds residents that are training in the practice learn about medical home principles, transition services for adolescents, and the role of the practice in providing care coordination. Prior to this initiative, residents did not learn about the public health, community, and educational resources available to families of children with special health care needs.

In this model, each practice must designate a care coordinator, who then receives extensive training in the model and in using region-specific resource materials efficiently in the practice. Each practice learns to share the responsibility of care coordination and to engage in quality improvement through quarterly medical home meetings, led by the care coordinator.

This program began with a National Learning Collaborative in 2003 with two private practices. This model was revised in a key pilot after Hurricane Katrina, and that model has now been used to train 9 teaching practices in care coordination, for a total of 12 total practices trained. Three additional practices have been identified for training this year. This program began with Title V Block Grant funds but has been continued with funds from a HRSA Systems Integration Grant. Funds are available for 3 additional practices in the last year of the grant in 2014, which could conceivably capture every major primary care teaching practice in the state.

To date, every participating practice has demonstrated significant increases in Medical Home Index, a nationally used measure of medical home capacity. (note: medical home capacity looks at the family-centeredness, continuity, comprehensiveness, cultural sensitivity, compassion, and accessibility of the practice including types of insurance accepted and hours of operation). Also, every practice that has completed their two year contract with us has continued to implement the model and provide annual MHIs to us, except for two that were closed by LSU: Earl K. Long in Baton Rouge and UMC Pediatric Clinic in Lafayette.

Unfortunately, our statewide care coordinator supervisor has announced her retirement as of January 4. We plan to fill the position as long as block grant funds permit. After completing academic practices, we hope to take the model to large private practices

through "lunch and learn" events, thus increasing medical home capacity in the private sector.

Resource Information Workshops (RIWs): In July, CSHS held a successful follow-up meeting with its stakeholder group (FHF Directors and Program Managers from agencies participating in RIWs). Each FHF held 3 workshops during the first year of the 3 year grant, as agreed. Comparison of pre and post –tests from RIW participants showed an increase in knowledge of resources among front-line state agency staff. In addition to the agencies traditionally serving CYSHCN, the Office of Behavioral Health was added to the participating agencies for the upcoming year. Each FHF has agreed to conduct 3 workshops per year for the next two years to permit all agency frontline staff to participate.

Medicaid and Insurance Claim Denials: For the past year, OPH has launched on an effort to improve Medicaid and Insurance Claim collections by changing to a physician provider type when possible and by contracting for insurance billing on an agency level rather than a program level. Unfortunately, this coupled with the changes inherent in the changes in Medicaid with the advent of Bayou Health, have resulted in continued problems with denied claims, prohibiting programs from maximizing their revenue. Problems include many things including billing software glitches, staff difficulty in deciphering what is required of each plan, difficulty obtaining the required priorauthorizations, and staff learning to enter and bill appropriately. Administration is working to address these issues and we hope they are resolved soon.

Louisiana Birth Defects Monitoring Network (LBDMN): LBDMN is an active birth defects surveillance system designed to identify birth defects and work to prevent them through cluster investigation, data integration with environmental epi, preventive education and collaboration with the March of Dimes.

The LBDMN Program Manager resigned in July. The CSHS Program Manager is acting as Interim Program Manager. Meanwhile, we have made changes to the data collection specialist contract to improve retention and we have been in discussion with CDC to select a web-based software program from another state that can be adapted for Louisiana. We are also in the process of contracting with DB Sysgraph to develop an interface with vital records for birth defects and genetics, which will improve data quality.

The Genetics Program continues to provide metabolic screening for 28 conditions for every newborn in Louisiana, with follow-up of those with positive results, The program also provides Genetics Clinics in each region of the state, which in most regions use the same staff as the CSHS subspecialty clinics. The program also conducts surveillance for children with elevated lead levels, which can cause learning and behavior problems in children. The program recently lost its CDC grant that provided surveillance in the city

of New Orleans, but obtained another one year grant from the EPA to help maintain these efforts from the state office. The program provides in home assessments to determine the source of the lead for mandatory abatement. The one remaining administrative assistant for the program after lay-offs last year is out on medical leave after suffering a heart attack, but is expected to return in a few weeks.

Hearing, Speech and Vision ensures all birthing hospitals screen every newborn for hearing prior to hospital discharge. The program also provides follow-up of infants with positive screens to ensure accurate assessment and early intervention ,toddler hearing screening, and access to audiological services and cleft lip and palate speech services in Lafayette and Lake Charles where there are provider shortages.

In September HSV began the "Guide by your Side" program that pairs parents of newly diagnosed children with hearing loss with an experienced parent of a child with a hearing loss in their community. The "Guide" provides unbiased support for decisions that family will need to make regarding mode of communication and types of intervention for their child.

The program recently completed a National Learning Collaborative where they received national recognition for lowering their lost to follow-up rate of infants from 35% to 23%; the national average remains around 50%. They have been invited to present their experience at the next NICHQ learning collaborative and also at the Annual National Early Detection of Hearing and Intervention (EHDI) meeting this year.

The two Parent Consultants for the program will present info on Guide by Your Side as well as the Louisiana Hands and Voices Chapter for the upcoming Speech Pathologists and Audiologist I Louisiana Schools (SPALS) meeting Sept 27-28. Both programs provide parent support for families of children with hearing loss.

The HSV has recently revamped its website with information for families, professionals, and stakeholders: www.ehdi.dhh.la.gov.