

March 18, 2014

Office of Public Health Report to the DD Council

Action Learning Collaborative on MCOs and CYSHCN: The Title V CYSHCN Programs unit of OPH has applied to the Association of Maternal and Child Health Programs to participate in an Action Learning Collaborative (ACL) focused on Managed Care Organizations and CYSHCN. Our application was accepted. We will be one of 8 states that are in the process of transitioning CYSHCN from Medicaid to MCOs that are participating in the ACL. Each state must develop a team with representatives from Medicaid, Title V, Bayou Health, and the AAP to participate in a series of conference calls and a one day conference in Washington DC. The purpose of the ALC is to learn from other states' experiences to ensure access to comprehensive care for CYSHCN in MCOs. This is timely for Louisiana as Medicaid prepares to release the next RFP for Bayou Health Plans.

Children's Special Health Services: We are entering the final quarter of the Systems Integration Grant, which ends in June. Activities of this grant will continue with support from the Title V Block Grant. CSHS is requesting a one year no cost grant extension to permit completion of all grant-funded activities.

- **Family Resource Center (FRC)** continues to provide community based resource information for CYSHCN, with 97 encounters this past quarter. Most encounters occurred in the FRC and in specific clinics. This permits a much more comprehensive encounter than earlier waiting room encounters. FRC staff provided direct services in Botox, Spasticity, Muscular Dystrophy, and Neuromuscular clinics and in the inpatient Rehabilitation Unit.
- The FRC held a **rehabilitation conference** on January 9 called "Think Transition!" which emphasized the supports young people with disabilities need to transition successfully to adulthood. It was presented by staff of the FRC, parents of children with disabilities, and young people who had successfully transitioned. It was attended by 72 people. This was highly successful. A second conference to further the message is planned in April and will be followed by a Resource Information session with representatives from LRS, OCDD, and other state agencies.
- The FRC continues to depend on its **Advisory Board** of stakeholders, which consists of parents of CYSHCN, a youth with special needs who recently graduated from college, and key agency/department representatives from CHNOLA social work department, La Education, FHF, and others. The last meeting was February 13 and the next is planned for August 14.

- FRC staff stay current by participating on boards and in conferences. Staff attended the AMCHP conference in Wash DC and participate on the CHNOLA CARF Outcomes committee, OCDD stateholder meeting, and the long term supports and services public forum.
- **The Transportation Assistance Program** provided \$9,828 to 53 CSHS families for transportation to medical appointments during the last quarter. This includes hotel stipends for consultation/ procedures at distant hospitals when needed.
- CSHS continues to provide **care coordination assistance to academic practices**. Lectures were provided to LSU and Tulane Pediatric Residents on Medical Home, Developmental Screening, Care Coordination and Transition.
- **Development of Webinars and Noon Lunch and Learns continues for private pediatric practices**. These are scheduled to begin in July 2014 in collaboration with LSU HDC.
- CSHS is gearing up for its annual **Care Coordination Resource Mail-outs** to health care providers. These region-specific care coordination materials are sent annually to FQHCs, SBHCs, NCQA-certified medical homes, MD Needs Assessment survey responders, pediatric orthopedists and neurologists, school nurses, and school linkage committee members.
- **Resource Information Workshops (RIWs)** continue through contracts with FHF in each region to inform frontline staff who serve families CYSHCN of the eligibility requirements and services of other programs that also serve CYSHCN. FHF contracts will end in June, 2014. One RIW per year will be held in future years in each region by the CSHS Parent Liaison.

LA Birth Defects Monitoring Network (LBDMN) is entering into the final year of its CDC grant, which has permitted growth of the program into a statewide surveillance system. The grant had a 20% cut due to sequestration. All but 5% is expected to be restored soon. LBDMN is still undergoing development of its web-based software system, including remote access to hospital discharge codes through a secure network, final corrections in the new LEERS module for integration with vital records, and computer generated letters to parents that include local resources for their child born with a chronic congenital condition. Regional resources include key contact numbers for Early Steps, CSHS Clinics, FHF, FRC at Children's Hospital, LA Early Hearing Detection Intervention Services, and Genetics Services. Back data continues to be entered into the system manually from scanned records, with the goal of entering all data from 2005-2011 scanned records by May 2014. Data is not considered complete for three years after birth since many chronic conditions are not diagnosed until after the neonatal period.

Several data collection specialists have been invited to participate in the regional Fetal Infant Mortality Reviews. This is an opportunity to use the LBDMN data to inform infant mortality reviews with the ultimate goal of improving preventive efforts among judicial and medical agencies involved.

Recently Vital Records staff mapped LEERS birth certificate data of anencephaly and spina bifida occurrences in Louisiana and found rates to be under-reported. Collaboration with the LBDMN active surveillance system will permit improved data for analyses such as these and is an exciting opportunity for collaboration. Accurate surveillance data will permit more targeted prevention efforts.

Hearing, Speech and Vision: Louisiana's Early Hearing Detection and Intervention (LA EHDI) program is applying for new grant funding from the Oberkötter Foundation, a private foundation dedicated to helping all children who are deaf or hard of hearing (D/HH) reach their full potential. The Foundation focuses its efforts on supporting families who have chosen listening and spoken language for their child and on opportunities for children who are D/HH to develop social, emotional, language and educational skills. The foundation believes that to capitalize on the critical stages of cognitive and language development between birth and age five, families must have access to comprehensive information and quality services as quickly as possible. If the LA EHDI Program is awarded this grant, the program will develop and implement a specialized point of entry into early intervention in collaboration with LA Part C and the Louisiana Guide by Your Side (GBYS) Program and Southeast Area Health Education Consortium (SEAHEC) to ensure early and appropriate services for children who are D/HH.

Like LBDMN, the LA EHDI team is in the final stages of development of its new web based database, working with the system developer to find and correct all "bugs" in the system prior to system launch. The new system will enhance the capacity of the current LA EHDI-IS to collect screening, diagnostic and early intervention data in order to ensure that children and their families receive quality services, to assess Louisiana's progress toward meeting EHDI objectives and goals, and to ensure the validity of reportable information.

Several members of the team will be attending the national Early Hearing Detection and Intervention conference in Jacksonville, Florida next month. Jeanette Webb, the LA EHDI follow up coordinator has been asked to serve as a Quality Improvement Advisor based on Louisiana's current and previous performance in using Quality Improvement techniques, such as the Plan-Do-Study-Act (PDSA) model, to significantly improve LA EHDI's follow up rate. Once again, LA EHDI is a team that is taking the lead nationally in ensuring that children with hearing loss get needed intervention in a timely manner!

The Genetics Program will hold its next **lead advisory meeting** on March 27. This past quarter, the lead program sent out 493 letters to families in Orleans parish with blood levels between 5 ug/dL and 9.9 ng/dL regarding identification of lead sources in the home and proper steps to decrease exposure in toddlers, for a total of 1587 letters this year. The program sent letters to 107 families whose children had levels above 10 ug/dL, for a total of 661 children this year. The program provides follow-up for these children whose development is at risk due to exposure to lead and ensures environmental abatement when necessary.

All members of the new **Sickle Cell Commission** have been approved by the Governor's office. The second meeting of the commission will be scheduled shortly. This Commission is charged with developing an integrated, comprehensive system of care for individuals with sickle cell disease in LA. Sickle cell can cause life-long disability and early death through infections, stroke, organ damage, and other medical consequences of the disease.

Bill 157 by Kevin Pearson would add **blot spot screening for X-linked adrenoleukodystrophy** to the newborn screening panel. This is a devastating genetic disease that causes developmental regression, dementia, and death in children. Treatment is still experimental and involves "Lorenzo's oil" and stem cell transplants. Three states currently screening for ALD: New York, New Jersey and Connecticut. However, this screening is currently not recommended by the national HHS Discretionary Advisory Committee on Heritable Disorders in Newborns and Children or the American College of Medical Genetics, mostly because treatment for this disease is not yet standardized. DHH has not yet taken an official position on this bill.