

Office of Public Health Report to the DD Council

September 16, 2013

Children's Special Health Services: CSHS had its annual MCHB Title V Block Grant review in Dallas on August 22. The review went well; this year's review team was very thorough and many revisions were made to the grant at their request. One revision was that the document for public review was translated into Spanish. This is a summary of the block grant that is used for dissemination to families so that populations served by the block grant can review its activities and provide input. The summary for public input can be viewed on the CSHS website at:

<http://www.dhh.louisiana.gov/index.cfm/page/740>

Public input was solicited last May and will be solicited again next year prior to the block grant submission in July.

The topic of this year's Title V Director's Meeting was the Affordable Care Act. An excellent review of the Insurance Marketplace which will begin October 1 was provided. The Marketplace can be accessed at: www.HealthCare.gov. Families must have health insurance by January 1. Subsidies are available through the Marketplace for those making 100% to 400% FPL. In Louisiana, because there is no Medicaid expansion, families making 12% to 100% FPL can participate in the Marketplace to find health insurance, but will not be offered subsidies to help purchase insurance and will not have tax penalties for not having health insurance by January 1. Four organizations received federal Navigator Grants to assist families in Louisiana in meeting the enrollment deadline: Southern United Neighborhoods, Martin Luther King Health Center, Inc., Louisiana AHEC, and Capital Area Agency on Aging, District II, Inc. Each of these organizations will have certified Navigators who can help people to navigate the Marketplace and choose an appropriate plan.

CSHS will work with AHEC to assist families attending CSHS clinics and clinics that have implemented CSHS care coordination in obtaining health insurance. There is a special emphasis on getting the word out to people with developmental disabilities. This is especially important given the reduced eligibility for the Medicaid Purchase Plan.

The Family Resource Center provided community based resource information on 2269 resources to 222 clients in July and August. Steven Nguyen, the FRC Youth Liaison, is planning an event for September 20 for former rehab clients to learn about recreational activities for people with disabilities. Thuy Nguyen, the parent liaison in the FRC, provided in home translation services to assist a family with their educational

rights and attended their IEP meeting with them. The FRC also provided information for families of children with disabilities on Back to School topics via a table in the lobby between July 22- August 28. The FRC Advisory Board met August 29 and will meet again in February.

The FRC is hoping to host the 14th annual two day “Chronic Illness and Disabilities Conference” at Baylor via video streaming to interested Children’s Hospital staff, physicians and pediatric residents on Oct 17-18. The only available room will only seat about 20 people. Staff from neurology and rehabilitation departments will be targeted for participation to help improve awareness of the needs of youth with disabilities transitioning to adult services. CSHS is also providing funding for two staff members in rehab and the social work departments to attend the conference in Houston.

The **Transportation Assistance Program (TAP)** provided stipends to 23 families during July and August in regions 4,6,7 and 8. The TAP brochure was translated into Spanish. Funds for this program from the Systems Integration Grant will end, but OPH plans to continue this program using Title V Block Grant funds. \$40,000 per year has been budgeted for this activity.

The **Care Coordination Program** for academic practices is in its last year. By June the last 3 practices will have implemented the program so that all LSU and Tulane teaching practices will provide care coordination services. Beginning in July 2014, CSHS will offer lunch and learns with CME for primary care private practices on care coordination, autism screening and referral, and transition services for youth with special needs. This will be done in collaboration with AHEC, which has offered to provide lunch for the seminars.

Resource Information Workshops are in their third and final year. Seven programs that serve CYSHCN participate in the 27 workshops per year (3 per region) for a total of 81 workshops that will be completed by June 30. Pre and post tests show that with each of the three years of workshops, scores on pre-tests have successively improved, and post-tests have always documented improvement in knowledge of program services and eligibility when compared with pre-tests. Participants have expressed an interest in continuing the workshops after the current grant ends. CSHS plans to use Title V block grant funds for at least one workshop per region per year beginning in July 2014 to help sustain gains made.

Louisiana Birth Defects Monitoring Network (LBDMN), Louisiana’s birth defects surveillance system, is in the process of hiring its final Data Collection Specialist needed for statewide coverage. This is possible because of restoration of sequestration cuts to the CDC grant that helps to fund that program.

The web-based software and integration with vital records through LEERS is complete and ready for application testing. The program is waiting for a server from IT, and is on target for implementation by January 2014. This is also the target date for completion of electronic entry for all data from 2008-2011. It is anticipated that analysis of this most recent data will begin in February 2014. Analyses will always be 3 years behind, because birth defects data is not considered complete until a birth cohort is 3 years old. This is because of the late diagnosis for many birth defects that may not be evident while the infant is still in the birthing hospital.

The flier used to advertise the Family Resource Guide has been widely distributed to LBDMN reporting facilities in all regions except 6 and 8 (due to lack of a DCS in those regions). It has also been shared electronically with various stakeholder groups. The guide itself can be accessed electronically at: www.dhh.la.gov/frg or by visiting the LBDMN website at: www.dhh.la.gov/LBDMN. The guide is designed to assist families of children with birth defects to navigate various services for children with special health care needs. The resource guide will be continually updated. Feedback on the resource guide is welcome.

Louisiana's Early Hearing Detection and Intervention (LA EHDl) program of Hearing, Speech & Vision recently made revisions to their LA EHDl web page: www.ehdi.dhh.la.gov. On the first page are 5 buttons with direct links for stakeholders: medical home, audiologists, families, birthing facilities and early intervention. Each page follows essentially the same format which includes role, FAQs, forms, brochures, guidelines and resources. The web site also has a map directory that you can click on your area for a list of pediatric audiologists specific to the area requested. Visit the site and if you have any questions or suggestions, please contact wendy.jumonville@gmail.com

LA EHDl has also initiated a quarterly newsletter, **All Ears** to keep stakeholders informed on EHDl news. With all of the current news surrounding EHDl issues, it is anticipated that each issue of the newsletter will include news specific to a particular group of stakeholders. The newsletter is designed to provide EHDl stakeholders with current EHDl protocols, procedures, resources and other information. If you would like to be included on our email list for the newsletter, please send an email hsvla1@gmail.com

Members of the LA EHDl team will be participating in the LA AAP Pediatric Potpourri on Sept. 28 in Lafayette. Dr. Thiravat Choojitarom, LA Chapter Champion for EHDl will give a brief intro to EHDl. Team members will distribute laminated information sheets, on Guidelines for Medical Home Providers related to EHDl, and follow up reporting of hearing rescreening in pediatric offices, as well as the new website. Dr. "Choo", as he is referred to by team members, publicizes and educates his peers and stakeholders on

the importance of pediatrician participation in EHDI issues. His email is Thira.Choojitarom@ololrnc.com.

The Genetics Program will participate in the first meeting of the Sickle Cell Commission in Baton Rouge on October 15. This is a result of the last legislative session that passed a bill to form a commission to improve comprehensive care for people with sickle cell disease. Matt Valliere is the official DHH representative on the commission. Other legislative positions include hematologists from Children's Hospital and Tulane, representatives from the regional Sickle Cell Foundations, a senator and a representative from the House.

National lead week is October 20-26 and the genetics program is gearing up to get the word out on how to make homes lead free.