Office of Public Health Report to the DD Council

March 2017

Bureau of Family Health (BFH) Title V Children and Youth with Special Health Care Needs (CYSHCN) Programs

Council members will be asked to complete an annual survey regarding block grant activities. Please review the attached flyer about Title V activities before the meeting. The brief survey is on the back! Thanks so much for your input!

Children's Special Health Services:

- The Family Resource Center (FRC) at Children's Hospital, New Orleans
 (CHNOLA) continues to link Louisiana families with needed resources through
 CHNOLA clinics and the Rehabilitation Unit. The FRC parent liaison, Thuy
 Nguyen, continues to serve on the CHNOLA Commission on Accreditation of
 Rehabilitation Facilities (CARF) committee, providing family input and resource
 information for CHNOLA staff. The FRC links families with their local FHF for
 ongoing support.
 - The FRC continues to provide community-based resource information to clients: December 2016-February 2017: 188 total client encounters;
 402 resource needs identified; 381 resource needs met.
 - The FRC Advisory Board meets twice per year. The next Advisory Board meeting will be in June 2017.
 - FRC Community outreach this quarter:
 - 1/14/17 Jefferson Community Health Center Health Fair in Lafitte
 - 1/28/17 Jefferson Community Health Center Health Fair in Marrero
 - 2/9/17CSHS Resource Information Workshop in Lafayette
 - A CHNOLA resource fair, "Early Intervention (Zero to Three) and Transition at Age 3" is planned for April 11, 2017 from 11:30AM-1:30PM for CHNOLA staff.
- Transportation Assistance Program (TAP)
 - CSHS continues to provide needed transportation assistance for families to medical appointments/ procedures; November-January: 147 travel stipends totaling \$19,783.80 were provided to families.
- Educational Outreach re Developmental Screening, Care Coordination and Transition
 - The article, "Enhancing State Medical Home Capacity through a Care Coordination Technical Assistance Model" which describes our success in

improving medical home capacity of 10 academic primary care clinics by implementing care coordination was submitted and accepted with revisions by the Maternal and Child Health Journal. Revisions were submitted March 23. Care coordination assistance is available for any primary care pediatric practice in Louisiana that would like to implement care coordination following the model described.

- CSHS continues to provide ongoing technical assistance for 5 contracted Care Coordinator/Medical Home practices (1 in Lafayette and 4 in New Orleans, including LSU, Daughters of Charity, and Tulane)
- CSHS held a Resource Information Workshop on February 9, 2017 in the Lafayette Parish Sheriff's Office Public Safety Complex which offered 4 CE to nurses and social workers on the topics of developmental screening, transition to adult services, care coordination including resources for CYSHCN. Over 20 public health and community agencies participated as vendors. Representatives from OCDD (EarlySteps), DCFS, LRS, Head Start/Early Head Start, and Acadiana Area HSD provided brief orientations to their services. A concurrent family workshop featured presentations on Individualized Education Plans (IEPs), Transition, and Healthy Louisiana Plans. The workshop was well attended with 109 participants.
- CSHS is participating in a multi-state technical assistance program of the National MCH Workforce Development Center to improve developmental screening of young children in Louisiana. The "travel team", including Rose Viltz (CSHS parent liaison, Lafayette), Lindsey Vicknair (BFH Developmental Screening Coordinator), Maria Blanco (LSUHSC-HDC), and Megan Miron (Dept of Education), attended a training in Chapel Hill NC February 12-15 to launch the T.A. A larger Louisiana inter-agency workgroup participates in ongoing webinars and activities designed to help improve screening rates for developmental, autism, social-emotional and environmental concerns to promote timely entry into early intervention/mental health services for Louisiana children.
- The workgroup will launch a developmental screening pilot in Lafayette where Project Launch has already begun to improve screening for social emotional risk factors, with the goal of expanding the pilot statewide over the next five years.

Louisiana Birth Defects Surveillance Network (LBDMN):

The Data Collection Specialist position in Region 4/5, vacated 8/1/16, has been posted at www.LPHI.org and locally in Regions 4 and 5 with no response. This person obtains discharge information from birthing hospitals for infants with birth defects and uploads it into the program's software system. Candidates should have at least a bachelor degree in a science or health related field and

familiarity with medical records. This job offers flexible hours and great technical support!

Zika Birth Defects Surveillance Grant:

- 4 RN Clinical Liaisons have been hired to facilitate rapid microcephaly surveillance activities at each birthing hospital to facilitate identification of infants with congenital Zika infection. Zika activities help improve Louisiana's birth defects reporting system and prevention activities. An opening still exists for a RN clinical liaison in Region 7.
- An offer has been extended to a nurse for the Zika surveillance Project Manager position.
- In addition to the \$400,000 CDC Zika core grant, in December CDC awarded a \$200,000 supplemental grant to the LBDMN program for January 1 July 31, 2017. This grant will enhance rapid surveillance activities including data integration with newborn hearing screening, updating of LA birth certificate applications, and resource materials for multi-cultural providers to encourage developmental screening, referral to Early Steps, and care coordination activities.
- Bi-weekly reporting to CDC continues of all 2016 birth outcomes with birth defects potentially associated with maternal Zika exposure. To date, we have reported five total cases. One case involved travel associated maternal Zika exposure; which resulted in fetal demise at 37 weeks gestation. In the other four cases, maternal Zika exposure was not involved.
- Prevention! Use insect repellent with DEET picaridin, IR3535, or oil of lemon eucalyptus (para-menthane-3, 8-diol) when outdoors even during the daylight hours. Drain standing water around your house. Avoid travel to infected regions. Practice safe sex and pregnancy planning following CDC guidelines for Zika exposure. See CDC Fact Sheets http://www.cdc.gov/zika/fs-posters/

Hearing, Speech and Vision:

Louisiana Hands and Voices (H & V) and the Guide By Your Side (GBYS) program, parent driven support groups for deaf and hard of hearing (D/HH) children and their families, recently hosted Molly Martzke, a member of the national H & V executive office for a 2 day session on Strategic Planning for non-profits. As a result of the strategic planning, the group decided that one of their primary goals should be to increase membership and expand their availability to all areas of the state.

Guide By Your Side™ is a program from national H & V that provides emotional support and unbiased information from trained parent guides to families of newly identified children who are D/HH. All of the parent guides are parents of a D/HH child. Guides help parents to identify communication options for their child offering unbiased help. Guides also help connect families with other families with children who are D/HH.

In March, the GBYS parent guides hosted a training for parents interested in learning more about the support group. Approximately 20 parents attended, with several expressing interest in becoming trained parent guides. One of the hosting parents summed it up saying "The best thing we did for our family was to get involved with the Guide By Your Side program. It made a huge difference in our knowledge and outlook regarding our daughter's future."

For more information about Guide By Your Side, please contact Jill Guidry at 337-515-5774 or email:jill.guidry@la.gov

- LA EHDI Early Intervention Consortium: On March 30 the EHDI team will sponsor a consortium of professionals and parents involved in Early Intervention (EI) for D/HH infants and very young children, including school system providers, educational audiologists, EarlySteps providers, Parent Pupil Education Program staff and others who provide services to young D/HH. The group plans to:
 - Assess the status of early intervention for children who are D/HH in Louisiana for each of the 12 goals in the Best Practice Guidelines of the Joint Committee on Infant Hearing
 - o Prioritize needs and goals to be addressed
 - o Determine aims and strategies for quality improvement

The Consortium will aid in ensuring that every child in Louisiana who is D/HH receives timely and appropriate intervention to maximize developmental outcomes.

Genetic Diseases Program: The lab anticipates adding Severe Combined Immunodeficiency (SCID) to the newborn screening panel in May 2017.

Childhood Lead and Healthy Homes:

- The program has completed the environmental review phase of the Lead Based Paint Hazard Control Grant. The purpose of this grant is to remediate homes of children with elevated blood lead levels where the source of lead poisoning is lead based paint. The program is working with HUD and the Office of State Procurement to put out a bid for contractors.
- Due to concern regarding possible contamination of water in the St. Joseph water supply, the program has participated on several calls with the state health officer to assess the threat to children under 6 and to determine other sources of

lead in homes with lead levels > 50ppb. An environmental assessment was performed on 30 homes and the program is waiting for the results to be compiled.