

Office of Public Health
Quarterly Report to the DD Council
(December 2014)

Update/progress on agency initiatives:

Children's Special Health Services continues its services through the **Family Resource Center (FRC)** at Children's Hospital. From Sept-November 2014 they provided 78 client encounters in the FRC and in Botox, spasticity, muscular dystrophy and neuromuscular clinics and in the inpatient rehab unit. Requests were made for 436 resources; 275 (76%) of these were met. The Youth Liaison, Steven Nguyen, provided FHF contact information, CSHS FRC brochure, and resource information to youth and their families in the inpatient rehab unit.

Steven was also selected to participate in the next class of Partners in Policymaking that begins in January.

The FRC Nurse Supervisor and the Title V CYSHCN Director (Dr. Sue Berry) met with Wyatt Howell, the CHNOLA COO, and provided an overview of the FRC. He was very supportive and said he wanted to expand opportunities for parent input at CHNOLA.

The FRC Advisory Board met November 20. Recommendations were made for 2015 programs to be offered to CHNOLA staff:

- Habilitation program---504 Services for Children with Chronic Illnesses
- Resource Fair for CHNOLA staff featuring agencies that serve CYSHCN
- CE program for nurses and social workers—Youth Health Care Transition
- Broadcast 16th Annual Chronic Illness & Disability Conference from Baylor

- Next Advisory Board meeting is planned for April 21, 2015.

The **Transportation Assistance Program** provided stipends to 86 families in regions 4,6,7,8 and 9 from Sept-November 2014. Stipends totaled \$15,083.28.

Care Coordination in academic practices wrapped up in June. All primary care practices that implemented care coordination over at least a two year period showed significant improvement in medical home capacity in all domains! This project was accepted for presentation at the annual **2015 Association of Maternal and Child Health Programs (AMCHP) Conference** to be held in January in Washington, DC. The presentation will be a one hour workshop shared with the California Care Coordination Collaborative Team. The care coordinator supervisor continues to provide updated resource information to all practices that have implemented the CSHS care coordination model.

Dr. Berry and the Nurse Care Coordinator Supervisor met with Dr. Rebecca Gee on October 20 to discuss expansion of care coordination implementation by Bayou Health Plans, as per the AMCHP Action Learning Collaborative strategic plan. Dr. Gee suggested exploring a pilot project to compare cost savings and health outcomes between practices with MCO supported care coordination and control practices in a designated area of the state. This is currently under discussion with one of the MCO plans.

The Care Coordinator Supervisor (Patti Barovechio) and Lauren Giovingo, psychologist from LSU HDC, have launched the Lunch and Learns on Caring for Children and Youth with Special Needs. They provided the Developmental Screening and Surveillance module to pediatric residents and the Medical Home webinar module to 64 nurses and

social workers in Shreveport on November 18 and 19. Four of the webinars continue to be available for lunch and learn in person conferences to primary care practices, offering CME to social workers, physicians and nurses.

CSHS piloted its new **Resource Information Workshops** model during Families Helping Families at the Crossroads' Annual Education Conference. Families, state, and regional agencies were invited to attend. The agenda consisted of two guest speakers focusing on education issues for CYSHCN and 10-15 presentations by State agencies. Community agencies were given five minutes to present from their booth. Evaluation responses suggested several changes in format for future workshops to increase their understanding of state agency services, which will be incorporated. Attendees recommended repeat workshops 1-2 times per year.

The Title V Needs Assessment is underway. This is only conducted every 5 years. It is mandated by the Title V Block Grant and is used to determine state priorities and five year plans for Title V programs for children and youth with special healthcare needs.

CSHS is conducting 2 focus groups in each of Regions 1, 2, 6, 7, and 8 beginning Thursday, December 4, 2014. The following research questions will be addressed during focus group discussions:

- What are the main health care needs of children with special health care needs and their families?
- What are the main barriers that children with special health care needs and their families face in *accessing the care* they need?
- What facilitates access to health care and support services for children with special health care needs and their families?
- What are families' experiences with care coordination?
- What are the main services and supports that youth with special health needs require to transition to adult healthcare, work, and independence?
- What do families of children with special health care needs see as solutions to the identified challenges and barriers?

In addition, CSHS is conducting a statewide survey of primary care pediatricians and family practice physicians to learn more about key components of medical care provided for children and adolescents. Results of both of these activities will be used to develop the five year strategic plan.

The **Childhood Lead and Healthy Homes program** had a successful Lead Poisoning Prevention Week from October 19-25. Children ingest lead from soil or from peeling paint from old houses. Lead has also been found to be on or in some Mardi Gras beads, which can lead to exposure when toddlers put them in their mouths. Lead ingestion can cause ADHD, learning problems, speech and language delays, and behavioral issues. Several educational activities were held around the state to increase awareness of the importance of lead testing in all children ages 12 and 24 months of age, or when there is risk of exposure. Only 16% of children in Louisiana are tested for lead. Lead testing has also been added to WIC clinics. On January 6 the program will launch an educational campaign to teach parents how to keep their children lead-safe along parade routes.

The **LA Early Hearing Detection and Intervention Program (EHDI)** is in the process of making newborn hearing screen results available online to providers. The software is finally complete and the program is piloting the system with a small group of audiologists. An online training will be developed before the system is made available to audiologists and pediatricians who register with the system, following HIPPA regulations. This will greatly improve follow-up of children who have positive hearing screens at birth, and will make appropriate intervention easier to implement and to

track. Early intervention of hearing loss is essential to promote language development and reading and school success.

Parent follow-up coordinators in the EHDI program work closely with Louisiana's chapter of ***Hands & Voices***, which is a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Outreach activities, parent/professionals collaboration, and advocacy efforts are focused on enabling deaf and hard of hearing children to reach their highest potential. They recently hosted the ***First Annual Guide By Your Side Family Conference for Parents of Children who are Deaf or Hard of Hearing*** held in Lafayette in November 2014. The conference included sessions on understanding the IEP, and transitioning to preschool, to middle school, to high school and beyond. Guest speaker for the conference was Karen Putz, mom to three deaf and hard of hearing children and an advocate for families with deaf and hard of hearing children.

Several Parent Guides from ***LA EHDI Guide by Your Side (GBYS) Program*** have attended workshops hosted by Families Helping Families (FHF) on IEP development and school transition. FHF will also contact Parent Guides when they receive a request to work with a family of a deaf or hard of hearing child. Parent Guides provide support to families who are transitioning from Early Steps into the school system as needed. They will also meet with families of hard of hearing children prior to IEP meetings, and attend the IEP meeting as requested by the family. Additionally, Parent Guides are available to provide information to school personnel who are unfamiliar with having a deaf or hard of hearing child in their class.

Current LA EHDI activities involve obtaining a Release of Information to acquire a copy of developmental assessments and Individualized Family Service Plans (IFSP) from Early Steps for children with hearing loss. Over the next 3 years LA EHDI will be working on the development of an MOU between LA EHDI, PPEP and Early Steps to define timelines and reporting responsibilities, and to improve coordination and data sharing between programs.

January 2015 is National Birth Defects Prevention month. The 2015 theme is "Making Healthy Choices to Prevent Birth Defects. The goal for 2015 is to continue to increase awareness that birth defects are "Common, Costly and Critical" and to offer steps that can be taken by professionals, community groups, and the public to prevent birth defects. Some of the new resources include sample letters to health care providers, a factsheet for policy makers, resources for grandparents of children with birth defects, and tailored materials for local health department. We will share the electronic package with more than 300 partners and stakeholders in all Louisiana public health units, school-based health centers, federally qualified health centers, all CSHS contract providers, and student health centers of all universities and colleges. The materials can be accessed at <http://www.nbdpn.org/bdpm2015.php>

LBDMN has a new program brochure, which has been distributed to all reporting birth hospital nurseries for family referrals. This brochure is intended to promote our program to families of children with birth defects, partner agencies, policy makers, agencies, and researchers.

Status of agency's activities/participation on DDC plan initiatives and impact (if applicable) NA

Status of Council recommendations to agency (if applicable) NA