

**MINUTES**  
**STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION OF HEARING IMPAIRED**  
**INFANTS**

**Quarterly Council Meeting**  
**Thursday, August 21, 2014**  
**3101 West Napoleon Avenue**  
**Metairie, LA 70001**

**COUNCIL MEMBERS PRESENT:** Thiravat Choojitarom, Naomi DeDual, Gina Easterly (phone [difficulties with connection], Linda Frantz, Juan Gershanik, Jill Guidry, Penny Hakim, Nancy Hicks (by phone), Anita Jeyakumar, Cynthia Suire, Alla Tarasyuk,

**COUNCIL MEMBERS ABSENT:** Barbara Gordon-Wendt

**GUESTS PRESENT:** Andy Amodn, Dr. Nancy Benham, Dana Carlisle-Hubbard, Brynn Millet, Victoria Flis, Patti Moss, Houston Moss, Rana Ottallah, Paula Rodriguez

**EHDI team present:** Marbely Barahona, Terri Mohren, Melinda Peat, Mariah Ranko, Mary Jo Smith, Tri Tran, Jeanette Webb (by phone)

The meeting was called to order by Dr. Choojitarom at 10:00 am. The minutes from the May 29, 2014 meeting were approved [Motion by Dr. Jeyakumar and second by Dr. Gershanik] with a unanimous vote of attending Council members. Council member attendees and guests introduced themselves.

**Presentations from Parents:**

Mallory Brown and Marilo Rivera shared (at the request of council member, Linda Frantz) parental concerns that followed their children's hearing loss diagnosis regarding early intervention providers, support and resources, and services for children aged 3-5 years with hearing loss. Both parents had feelings of worry, frustration, helplessness, lack of information available or clear definable plan or where to turn for knowledgeable help.

Terri Mohren shared with council members that now systems are in place for contact with newly diagnosed families through referrals to early intervention system (EarlySteps), PPEP (persons knowledgeable about hearing loss), and family support (GBYS). Dr. Gershanik recognized (i) the parent group (GBYS) can be quite helpful with these issues, (ii) there is a lot of emphasis on hearing screening and routine follow-up, and (iii) we have come a long way with in early diagnosis. Dr. Jeyakumar discussed wording possibly used by physicians to parents is critical (...no it will not be fine, ... may be fine, but should be worried).

Penny shared that often parents may misunderstand physicians, being overwhelmed and possibly in denial. Dr. Jeyakumar reiterated that physicians should be careful about how and what they say. Dr. Choojitarom stated he was concerned that these families did not know about us. Concerns mentioned about high turnover and varied knowledge of Family Service Coordinators through ES.

Rana Ottallah addressed council regarding:

- (i) challenges in area of Deaf Education in Louisiana regarding lack of service providers, deaf education programs, interpreters, and appropriate access, transition services;
- (ii) support for legislation to amend the Deaf Child's Bill of Rights §1960. She proposes changing "entitled to" to "shall have"; and
- (iii) opposition to Act 833 because it may allow the schools to graduate children who are not qualified, who do not meet minimum standards.

Naomi DeDual shares that this legislation is for students failing 2 out of 3 years of standardized testing, not all sped students and LAA1 students are ineligible. Dr. Choojitarom states that it depends on implementation. While we, as individuals may support or oppose it, as a council we cannot testify nor endorse any legislation. Dr. Choojitarom mentioned possibly contacting Developmental Disability Council to see what their take is on Act 833.

#### **Old Business:**

**LTF/LTD Follow up Report:** Jeanette Webb provided an update on LTF/LTD. The LFT rate was 30% in 2013, and 27% for first Quarter 2014. PDSA will specifically targeting Alexandria and Region 7.

#### **Early Intervention and Educational Issues:**

Dr. Benham, LSD Director, shared about reorganization at LSDVI. Prior PPEP was separate. Now returned to the school side. Dr. Benham closer to be more directly involved. She is looking to make changes – services to get to families. Understand frustrations -- transcend across states are somewhat same -- not only unique to Louisiana. They are doing best getting info out to families. Also concerned about teacher training programs in Louisiana, UNO may be losing theirs due to retirement of professor. Dr. Benham said she would be going to bat for PPEP.

#### **Council Discussion of New Business**

##### **Infants Born Outside of Hospitals:**

Dr. Choojitarom asked if we have a legal opinion regarding required newborn screening of infants born outside of hospitals. Melinda Peat says that 'off the record' it seems there are loopholes in legislation could allow some through without screening all. Seems to say birthing centers are required, and implies that those other than hospital, nurse midwives may not be included.

**EHDI Epidemiologist report:**

Dr. Tri Tran introduced Dr. Audu Amodu from Tulane to deliver report on La EHDI Surveillance System Evaluation Report about the program and some statistical data. For ease of reference, it is attached hereto as Attachment A.

**Universal CMV testing:** Much discussion on medical as well as cost/benefit areas. May have just the Providers address this.

**Next Advisory Council Meeting:**

The next Advisory Council meeting will convene Thursday, November 13, 2014 from 10:00 a.m. to 12:00 p.m. Dr. Choojitarom suggested the next meeting be in Baton Rouge to accommodate some council members and also suggested a rotating location since the New Orleans location is also quite convenient for many council members.

**Adjournment:**

A motion to adjourn the meeting was made by Dr. Choojitarom and seconded by Nancy Hicks. By unanimous vote the meeting was adjourned at 12:00pm. The meeting was then ended with a call for brief Committee meetings owing to the lateness of the hour.

