

MINUTES
STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION OF HEARING IMPAIRED
INFANTS

Quarterly Council Meeting
Thursday, May 29, 2014
Bienville Building, Room 173, 628 North 4th Street
Baton Rouge, LA 70802

COUNCIL MEMBERS PRESENT: Thiravat Choojitarom, Naomi DeDual, Gina Easterly, Jill Guidry, Penny Hakim, Nancy Hicks, Anita Jeyakumar, Alla Tarasyuk

COUNCIL MEMBERS ABSENT: Linda Frantz, Juan Gershanik, Barbara Gordon-Wendt, Staci Sullivan

GUESTS PRESENT: Sonya Myers attended in Cynthia Suire's absence.

The meeting was called to order by Dr. Choojitarom at 10:36 am. The minutes from the February 13, 2014 meeting were adjusted and approved with a unanimous vote of attending Council members. Council member attendees and guests introduced themselves. Gina so kindly provided speakerphone, and Naomi arranged complimentary parking (Thanks, guys!).

Old Business:

LA EHDI Database Report: Database is in process of testing. Dummy data was sent and results have been submitted. It is estimated possible results in June or July. Vendor is DB Sysgraph.

Louisiana Hands & Voices™ Report: Jill Guidry provided the update for LA Hands & Voices. She provided copies of the newsletter with summer activities, list of summer camps, info on annual Rock'n'Bowl fundraiser. Sponsors and donations are being sought through mailouts and phone calls. Information regarding the event is also included on their website. The quarterly newsletter is in its third year of production. The group would asked for suggestions for additional avenues to share electronically. Nancy Hicks suggested cooperative distribution through Families Helping Families. Wendy Jumonville offered to provide the newsletter electronically to all audiologists in the state. Jeanette Webb also suggested fax blasts could be used to send the information. Dr. Choojitarom will contact OLOL and LA-AAP for information distribution.

LTF/LTD Follow up Report: Jeanette Webb provided an update on LTF/LTD. The LFT rate for 2013 was 30%, which was a significant increase from 2012 with a rate of 26%. What caused the increase? The EHDI team is conducting more

quality improvement projects. The LTF reported rate decreased from 15% to 14%. Physicians and audiologists report this. The LTD rate, the % of infants that there is no report for, has increased from 11% to 16%. The In Process rate, the % of infants who need more followup, has been very stable, increasing from 5.18% to 6.3%.

In 2010, there was a drop in all percentages. This was due to the addition of 3 staff members, a FollowUp Coordinator, and a helper. In 2011, the NICHQ Collaboration began. Finally, in 2012, the PCP fax back project began which increased coordination with the medical home.

So what happened in 2013 causing the change? Hospital reports were created by hospital focusing on LTD numbers. The number of births should be the focus. Some hospitals are reverting back to not reporting. Sustainability in reporting is needed. Some suggested ideas include contacting the provider to discuss their not reporting and copy the hospital liaison on the e-mail. Including information that the PCP will be notified could prove helpful. Dr. Choojitarom suggested working on education at the hospital audiologist level. Smaller hospitals could possibly bring the infant back to the hospital for testing. Encourage them to schedule follow up. There are many nuances with hospitals. What can we do to work with them? Dr. Jeyakumar asked if it is feasible for hospitals to bring them back in as outpatients. Jeanette suggested checking with the hospitals to see how they could handle that. Also, see what's best for the family. Wendy Jumonville suggested the hospitals could bill the same as inpatients and use the same RN's for screening. Dr. Jeyakumar asked how many times should the infant be rescreened, because some infants are rescreened many times within the first month, resulting in the parent not following through. Wendy said they should be rescreened once, and then see an audiologist if they fail the rescreen. The guidelines state there should be only one rescreen. The EHDI team should contact those not adhering to the pediatric guidelines. Dr. Choojitarom asked if the new database would help identify those not following through with rescreening. Jeanette said "In Process" will show up with no diagnosis. She will receive an e-mail and will be able to investigate. The current database is riddled with bad data that has been entered incorrectly, reported incorrectly, etc. Data has improved since October, 2013 due to a new staff member serving as Data Entry Clerk. "In Process" has dropped to 4% through investigation. Wendy suggested a letter be sent to high LTF hospitals from the Advisory Council. Nancy Hicks asked if there are any incentives for hospitals to report, which Wendy replied there is not. Naomi DeDual asked if all hospital rates could be published and sent to all hospitals. Wendy said that was once utilized. A letter from someone different may be helpful.

Wendy said there are nine hospitals with poor reporting. Gina Easterly asked what process was previously used. Wendy said site visits occurred, along with

sending lists of names of those infants LTF. Jeanette said timeliness became an issue. Naomi asked if there is a personnel issue, if turnover affects reporting, and if there is a workload issue. Wendy replied yes to all. Gina suggested conducting phone surveys and Nancy suggested publishing rankings and timeliness of reporting and providing this information to the hospital in addition to the audiology supervisor. Naomi asked if reports could be sent via e-mail. Jeanette said that had been attempted, yet errors were abundant. The new database could offer an opportunity to attempt this again. A test could be conducted with one of the 9 hospitals with poor reporting.

Penny Hakim shared concern regarding families in remote areas experiencing a time delay in receiving services due to having to wait for appointments to receive prescriptions to see their audiologist. Dr. Jeyakumar stated a pediatrician can write a prescription for hearing aid clearance. She suggested Penny tell the parents to talk to their pediatrician. Also, the audiologist could be involved to call the ENT. Dr. Choojitarom suggested providing parents with a process map. He stated that LTF will be discussed at the next meeting, but in the meantime, he suggested trying the letters and ranking.

Early Intervention and Educational Issues:

The need for more early intervention was a topic at the national EHDI conference.

Naomi DeDual stated there is recent legislation being sponsored by 2 state legislators which would allow for an alternate route (provide an alternate measure) for students who fail 2 out of 3 years. Those in the deaf community are currently not supported by any alternate measure. Rana Ottallah provided information from the National Association for the Deaf to the legislative Education Committee. Students' achievement helps create a score for schools, which is in turn used in revenue allocation and other areas. Opponents of the legislation do not want the value of a diploma to be watered down. Proponents want schools to allow for another route for students to receive a diploma. Students utilizing ASL, for example, have difficulties passing the required reading level for the LEAP standardized test. The IEP team should be able to use other measures. The legislation has passed at the committee level, and, as Nancy Hicks stated, the final vote was supposed to have occurred on 5/28/14. She was unsure of the outcome.

A few questions arose: 1) Is a diploma more important than a Certificate of Achievement? 2) Would a student be required to achieve all Carnegie units? 3) What standard does Gallaudet use? 4) Would some school systems use the alternate measure as a crutch? Nancy said all states administer standardized tests, but not all states tie test results to receiving a diploma. Louisiana does, and also requires high stakes testing for diploma receipt. Naomi stated educators requested guidance from BESE on the topic.

Dr. Choojitarom discussed coordination with PPEP. Gina stated she is not sure how much PPEP supports transition from ES to LEA. There is currently a lack of PPEP staff. Nancy Hicks asked, if there funding is a line item in the state budget, why is there not a full staff? Jill Guidry stated that over the years funds for Outreach/PPEP services has been decreased. Naomi said she did not believe it is a line item, but a portion of the LSD's budget. Dr. Choojitarom suggested the Advisory Council invite Kevin Lemoine and Dr. Nancy Benham to the next meeting to discuss this topic.

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 is still working with DHH legal to receive their opinion.

EHDI Meeting:

There was much discussion of care coordination at the state meeting.

An app for navigating hearing loss in Louisiana was discussed.

Some states use WIC offices for screening.

CMV-CMV causes 20% of non-syndromic hearing loss. Oregon is looking into universal CMV screening. Dr. Jeyakumar stated CMV screening must be included in newborn screenings, that an infant cannot be screened after 2 weeks of age.

She said it is the most common cause of acquired hearing loss and if it is caught early enough and treated, the hearing loss can be reversed. Nancy asked if there would need to be a legislative bill to require the screening. Dr. Choojitarom suggested working with DHH to add the testing. He also suggested asking Dr. Berry if it would be easy to add the testing to the newborn screening. He asked if the AAP had guidelines for treatment. Dr. Jeyakumar said traditional treatment included IV treatment, but now oral medication is utilized. She said there is no firm protocol yet, but the hearing loss is preventable.

Next Advisory Council Meeting:

The next Advisory Council meeting will convene Thursday, August 21, 2014 from 10:00 a.m. to 12:00 p.m. at the DHH/OPH Lab Building Conference Room, 3101 West Napoleon Avenue, Metairie, Louisiana 70001. Dr. Choojitarom suggested the next meeting be in New Orleans to accommodate some council members and also suggested a rotating location since the Baton Rouge 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.

