

MINUTES
STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION
OF HEARING IMPAIRED INFANTS

Quarterly Council Meeting
Tuesday, May 2, 2017
LaPlace, Louisiana

COUNCIL MEMBERS PRESENT: Susannah Boudreaux, Thiravat Choojitarom, Gina Easterly, Jill Guidry, Penny Hakim, Sohith Kanotra, Megan Miron, Patti Moss, Staci Sullivan (by phone), Alla Tarasyuk

COUNCIL MEMBERS ABSENT: Amy D'Alfonso, Leigh Ann Norman

GUESTS PRESENT: Margaret Berry, Jeanette Webb, Melinda Peat, Wendy Jumonville, Mary Liz Crigler, Amy Brown, Morgan Taylor

The meeting was called to order by Dr. Choo at 10:00 am. The minutes from the previous meeting were approved with unanimous vote of attending Council. Council member attendees and guests introduced themselves.

New Business. Council members were queried, and there is no new business at this time.

Council Discussion of Old Business

Loss to Follow up Report: Jeanette Webb reports on Lost to Followup and Loss to Documentation. It is a little bit better than reported at last council meeting. Then it was a little over 25% of babies that failed at NHS that we have considered as lost. They have not shown up for their outpatient rescreen; we can't get in touch with them. Now it's down a little bit to **24%**. There are two pieces to the lost to followup: we have no documentation after they have left the hospital (significantly down from in the past) and the ones that are reported that they cancelled their appointment or no showed for their appointment or audiology is unable to get in touch with them (which is down to 9% from 14%). There has been great improvement in getting providers to report what is going on. That is so important because until we know they have been lost, we really can't act on it. We do send faxes to the PCPs, pediatricians and we send out letters. But until the audiolotist reports to us and gives us a phone number, because we do not get phone numbers from the LEARS vital records data dump into our database. So otherwise until we get that information, we can only contact parents through mail or through their pediatrician. One of the things we are about to test is texting to parents. This has proven to be helpful in several states, Utah and Indiana. LA EHDI is modeling after them. At this point we're waiting on Legal Dept. approval because there are hoops we have to jump through because of HIPPA. It is currently with Melinda to contact legal. Dr. Choo queried if this success seems to be from the electronic system. Jeanette indicates that they are able to get users to better understand the importance of timely reporting. The new database system is letting us contact PCPs and parent letters in a very timely manner. Brittany Toepfer, our new administrative assistant, is sending letters right after birth and notifying the pediatrician that the baby has an upcoming followup appointment. There has been an increase in users to the database with more accurate and timeliness. Another way that we are looking into contacting families is through Facebook. Kentucky has also been using Facebook. Just to see if there's identifying information. We can private message them in FB with just generic information and we're going to test doing that. We

have to go through Legal and BMAC. Gina Easterly suggests contacting Schulman; she's a BMAC rep. Dr. Konatra shared his experiences with Facebook, adding that he works a lot with his tracheotomized babies and there is a dedicated Facebook page run by a patient's mom. The families love it; it's a source of information. Everyone is on Facebook. So if we talk about the situation with an EHDI Facebook page. Baby fails the hearing test, before they leave the hospital they could be hooked up with it. Marketing is available there easily, allowing targeting of population. It could be a great source for education. If it's a closed group, parents have opted in. There could be a Facebook page that could be run by a parent, or you could have a Facebook page that is run by the state which would go with all the hurdles and headaches of HIPPA controls. Wendy Jumonville suggested we could possibly use the Hands & Voices Facebook page but bringing it to the hospital level, which hasn't been done. We could send anything to Hands & Voices to post that information. It was agreed that is a possibility rather than reinventing the wheel.

EI Consortium. Wendy Jumonville reported on the recent Early Intervention Consortium. A handout was provided and is attached as Attachment "A". The Consortium was held in March, and it was grant funded. It was a meeting to get parents and professionals involved in looking at what the goal in our state should be in terms of early intervention. There were 62 parents and professionals in attendance. This was above our expectations. The participants were given a survey ahead of time to rate their understanding of early intervention in our state and to rank their priorities. This was done via survey monkey. The meeting was led by a facilitator and she led discussions on that survey. There were eight different groups for the day. Each group discussed that survey and was given certain goals to discuss. In 2013 the Joint Commission on Infant Hearing produced a supplement to their position paper. That supplement was on 12 goals on early intervention. The day was structured around looking at the 12 goals and how that could be addressed. The goals that were chosen are goal 3 and goal 12. Goal 3 states from JCIH that all children who are deaf and hard of hearing from birth to three years of age have EI providers who have the professional qualifications and skills to optimize the child's development and the child and families wellbeing. On the handout are the bullet points on how that might be achieved, everything from contacting universities, consulting with other states, a resource guide so that we know where those services in the states to getting early intervention access to our database so that we can get these services reported. The other goal chose was goal 12. It reads as best practices are increasingly identified and implemented, all child who are deaf and hard of hearing and their families will be insured of fidelity in the implementation of the intervention they receive. The bullet points that came out of that are: evidence based practice, survey parents to see that the services they are receiving from these providers and that we develop some best practice guidelines and possibly mentoring programs. Participants then signed up for working groups for each goal. On May 11 and 12, there will be working group conference calls to talk about where to go from here. Dr. Kanotra was in attendance and added that the conference was very well put together. He reiterated what Jeanette said earlier that the two main points are communication and education. Wendy further mentioned that if there are members of the Advisory Council who would like to participate in the EI Consortium workgroups, please send her an email and let her know so you can be connected. Terri will be presenting this at the last Louisiana Commission for the Deaf and that two of those members are going to participate on committees.

Early Intervention: Susannah Boudreaux shared about Parent Pupil Education Program for new members of the council. She shared that when a child is confirmed hearing loss, that information is shared with PPEP as well as Parent Guides. Parents are contacted within three days to let the parents know that they are there to provide them with education respective to their child's

hearing loss, provide them with resources, connect them with Early Steps, and connect them with other parents in their area so that they have those opportunities for socialization. At times, PPEP is getting a call from audiologists before they are receiving the referral. It is provided as an inkind service of the Louisiana School for the Deaf.

Parent Update: Jill Guidry provided update on Louisiana Hands & Voices. Picnics are planned around the state in different regions throughout the summer months. The first is in May, this coming Saturday, in New Orleans area. Thereafter, we will be in Shreveport, Lafayette, Lake Charles and Central Louisiana (Alexandria). Brochures for LA H&V and Guide By Your Side were provided to new Council members. This summer LA H&V is also updating its Resource Guide which is given to families of children newly identified with hearing loss; we want to ensure our resources are updated. Wendy Jumonville asked that when it is completed, the updated Resource Guide be sent to her as it is on the LA EHDI website. We're also tracking our information a little different way, so we can keep track of our reach.

Council Vacancies: The two vacancies are neonatologist and a representative for the Louisiana Commission for the Deaf.

Lead-K: Penny Hakim shared that she wanted to be sure the Advisory Council was aware of Lead-K, which is Language Equality and Acquisition for Deaf Kids. There are initiatives are going on across the states now, initially started in California. It's been hard getting things to get going, since initially not everyone was at the table representing all deaf kids. Penny has met personally with the lady who began this; there is a template that they use. There are currently 22 states actively working on this bill. Penny wanted to be sure that the Advisory Council was aware of it, and that if we do hear of it that we should be sure we have unbiased representation across all choices, full representation. The stakeholders all involved so that it's a good positive thing and its done in a way. Just like when we have our Deaf Summits, and we all stand together for the Deaf Child Bill of Rights. Dr. Choo mentioned that was something he wanted to mention too. He had heard of it at the last national EHDI conference, the movement for language policy for deaf and hard of hearing. In California, there is State Bill 210. I think you're right in that as a council we can certainly say that language development is vital for children. Penny mentions that we want to be sure that parent choice is present and that it's not mandated. Susannah mentioned that often parents feel that its being decided for them and they do not have a choice; Choo concurs, saying he had it noted that it almost seems as a binary choice for children with hearing loss.

JCIH Position Statement: Dr. Choo shared that there are new recommendations from JCIH that will be coming out soon. As a preview, he shared that before it was said that if you screen with ABR, you should rescreen with ABR. The new recommendation is that if you screen with ABR, you may rescreen with OAE. The idea behind that is it is much more available. Wendy Jumonville asks if that is only in the well baby population, and Choo confirms it is. It will be stated that the preference is for ABR, but if you don't have it then OAE. The maximum number of rescreens will be set at three; there is no current limit. Choo further mentions that at the last EHDI conference, there was much discussion of making deafness a pathology, looking at deaf as a culture as opposed to a pathology we need to fix. There were really long discussions on that.

Next Advisory Council Meeting:

The next Advisory Council meeting will convene July 24, 2017 in LaPlace.

atAdjournment:

A motion to adjourn the meeting was made by Dr. Choojitarom and seconded by Gina Easterly. By unanimous vote the meeting was adjourned at 12:00 pm with committees meeting briefly.

Committees:

Early Intervention Committee	Regulatory Compliance Committee	Education Committee/ Outreach
Terri Ibieta	Wendy Jumonville	Thira Choojitarom
Margaret Berry	Staci Sullivan	Jeanette Webb
Megan Miron	Penny Hakim	Jill Guidry
Sohit Kanotra		Melinda Peat
Gina Easterly		Patti Moss
Susannah Boudreaux		

