

MINUTES
STATE ADVISORY COUNCIL FOR EARLY IDENTIFICATION
OF HEARING IMPAIRED INFANTS

Quarterly Council Meeting
Tuesday, July 25, 2017
LaPlace, Louisiana

COUNCIL MEMBERS PRESENT: Susannah Boudreaux, Thiravat Choojitarom, Amy D'Alfonso (by phone), Gina Easterly, Jill Guidry, Penny Hakim, Sohith Kanotra, Patti Moss, Leigh Ann Norman

COUNCIL MEMBERS ABSENT: Megan Miron, Alla Tarasyuk

GUESTS PRESENT: Margaret Berry (by phone), Jeanette Webb (by phone), Wendy Jumonville (by phone), Tri Tran, Marbely Barahona, Ashael Barahona

The meeting was called to order by Dr. Choo at 10:00 am. The minutes from the previous meeting were reviewed and approved as provided with unanimous vote of attending Council.

Old Business:

Loss to Follow up Report: Jeanette Webb reports on Lost to Followup and Loss to Documentation. Followup for the grant period that ended April 2014 – March 2017 was 31.7%. For the grant just ended, 2016 births we are at 22.9%. So in that three year grant period we improved from 31.7% to 22.9%. Reducing Loss to Followup was the goal of Maternal Child Health grant. We have a lot of new activities we are starting, one of which is texting parents who have not yet returned for followup, started in early May 2017. In initiating the project, we've come across a few challenges: not having the correct numbers, not having wifi. At the next council meeting we will have some additional data to share for this initiative. Susannah's question: What is the national average for Lost to Followup? Jeanette reports that the national average that CDC reports based on 2014 births is at 34.4%, so we are much below the national average.

New Business:

Early Intervention for Children with Hearing Loss. Susannah Boudreaux shared a couple of handouts (Attachment 1 and 2, respectively), Parent Pupil Education Program's regular flyer and a handout showing PPEP staff, current and new staff, Nakiesha Owens and Ivette Perez. Rachelle, a former PPEP staff, is no longer working since her father is too sick for her to travel. Another former PPEP staff, Sydney is venturing out a new endeavor at the School for the Deaf. After much pleading, the school has agreed to open a second tract, offering classrooms that focus on listening and spoken language. They will begin in August, and begin with preschool and kindergarten classes at this point. If the numbers continue to come in and interest is show, each year they will add a new class. They look for that tract to go through elementary school, and then by then, a child will know which tract they decide to go in. Nakiesha is certified in deaf education with a specialization in preschool, she will be doing half of New Orleans and traveling north. Ivette Perez, comes from Florida, and she is also certified in deaf education and bilingual, so our Spanish speaking families will also have someone else who speaks their language. Ivette will be doing half of New Orleans and traveling south.

EI Consortium. Terri Ibieta provided report. Last council meeting, Wendy Jumonville had updated and provided that committees had formed from those in attendance. One committee was from Goal 3 from the JCIH recommendations for EI, stating that all children that are deaf or 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. So that committee, the first thing they have chosen to do is to put together a resource guide of providers who are currently available around the state. So the committee divided up the duties and each person is putting together for all the services for anyone deaf or hard of hearing for that region, some services are statewide, some private providers, specialized services, Early Steps, looking to get together a stateside directory. First getting the list together and then looking at what the needs are to proceed. Wendy Jumonville shared that the deadline for the first information gathered to go to Shannon, then she will have to go through it. Of course, some regions will be better than others, but they can look at what others have done. It will probably take a year to get the information together. Then, of course, it will need to be formatted into a similar format for each region. This will be something that can be updated, as changes will inevitably need to be changed and be an ongoing project. Possibly even next year, school system services could be added. It could become electronic; we could do lots of things with it. The other committee formed around Goal 12 from the JCIH recommendations, all children that are deaf and hard of hearing and their families can be ensured of the fidelity of the intervention they receive. . The first thing that committee has started with is a survey for families of children who are deaf or hard of hearing ages birth through five. They've looked at best practices and put into survey that will be sent to families. The survey will be sent in paper form, since we don't have email addresses on all families. However, in the cover letter, there will be a link to survey monkey so that the survey could be completed online. We are up to 30 questions (with 3 questions being open ended) and is four pages front and back. We need this feedback from the families to find out what is going on how and what needs to be improved, so we'd like to offer some incentive for the survey to be completed. So we're exploring with our funding source right now to see how we can do that so that we can possibly get a better response.

MCHB and CDC grant updates: Terri Ibieta provided a handout with one side MCHB (Attachment 3) and the other CDC (Attachment 4).

CDC grant. Center for Disease Control notice of award letter was just received. There were 46 states that received the basic grant. We also had the opportunity to apply competitively for the expanded grant to receive additional funding. We were 1 of 9 states who received an additional \$100,000 for expanded grant activities. So for the CDC grant, I put together the original grant goals, and as you can see its based around our LA Early Intervention Information system (our "IS"), based around surveillance, training and support to providers, partnerships, strategic intervention and dissemination of information and then the monitoring, analysis and evaluation. As you see on 5.4, to conduct data analysis to identify factors associated with Loss to Followup and Lost to Documentation. One of the reasons we were able to receive this award is because we have Dr. Tri Tran on our team. He will be conducting these expanded activities. Dr. Tran reports that the main purpose for the expanded tract activities is to focus on data analysis and evaluation. So we will provide the state data to the national EHDI program to analyze the nationwide data. So this will encompass only four years data, in 2020. Terri shares that there will be a kickoff for this grant and the expanded grant activities at the national conference.

MCHB grant. The purpose here is to develop a comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care targeted towards ensuring that on

newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis and early intervention. They want this purpose to be achieved by focusing increasing health professionals' engagement within and knowledge of the EHDI system, improving access to early intervention services and language acquisition, and improving family engagement, partnership and leadership within the EHDI program and systems. This grant is from April 1, 2017. It's a three year grant. To begin, we had 90 days to development a Memorandum of Understanding and partnership with an agency that provided family support. In Louisiana we were fortunate that we have Louisiana Hands & Voices, which is very active. We already had the Guide By Your Side program, and we already have the ASTra program. We were already ready to partner with them; all of the parents were already part of our program. The difference about the program now is that MCHB grant is requiring states to give 25% of their grant to the family to support agency. In Louisiana, really when we looked at our budget, that's about what we spend on them. We now have a formal agreement with Hands & Voices, and they will continue to provide the services they have always provided. MCHB told states these are the goals they will work on for this grant. The health professionals' engagement within the EHDI system is a new goal. There is a big concentration on early intervention. In past years, the focus was on screening, being sure all the babies are being screened. This last grant was on follow-up, being sure families follow-up. Now, this one is centered on early intervention, but it focuses on family engagement. Not just family to family support, but also getting families partnered, being an important part of the system. They are the consumers; they need to be part of the system.

Parent Update: Jill Guidry provided update on Louisiana Hands & Voices. LA HV has entered into the Memorandum of Understanding that Terri mentioned. We have had a busy year thus far. Picnics and activities were held around the state throughout the summer months in New Orleans, Shreveport, Lafayette, Lake Charles and Alexandria, and we were pleased with the turnout for those. Speaking of our GBYS program, we did double the number of parent guides we have working with families from 5 to 10, increasing our reach in the state. One of the new parent guides is the parent of a child who is hard of hearing, with the others parents of children who are deaf. We reach families through family contacts with GBYS families, by mail, Facebook and our website. Amy D'Alfonso shared that one of her former clients, who is the mom of a child with hearing loss, has just become a Deaf/Hard of Hearing Guide in Mississippi.

Council Vacancies: Dr. Choo's term is up, and he asked that if we know of a pediatrician who might be interested, please have them call him. Both parent positions are available, and will be filled by Marbely Barahona and Ashley Nielsen. The vacancies we are working on are neonatologist and a Deaf adult. Dr. Choo and Dr. Konotra will run this by neonatologists they know to see if there is interest. Council elections will need to be held at next meeting, and since our bylaws state that elections should happen at the next meeting. Dr. Choo will get with Melinda about elections too.

JCIH Position Statement: Dr. Choo has not gotten anything new on this yet, but it should be progressing through the bureaucracy but that it will probably come out in 2018. At last council meeting, Dr. Choo did give a bit of preview of the new JCIH position statement and that's about as much as Choo knows since then.

Next Advisory Council Meeting:

The next Advisory Council meeting will convene October 31, 2017 location TBA.

New Council member:

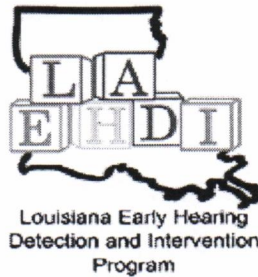
Leigh Ann Norman introduced herself as new council member. Leigh Ann is an audiologist at Willis Nighton Hospital in Shreveport. She feels honored to be here and hopes she can bring something to the council.

Adjournment:

A motion to adjourn the meeting was made by Dr. Choojitarom and seconded by Gina Easterly. By unanimous vote the meeting was adjourned at 11:40 pm with committees meeting briefly.

Committees:

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



Parent Pupil Education Program ~ PPEP



For Families of Children with Hearing Loss

PPEP is a No Cost, Parent Choice Program that provides Unbiased Information and Support.

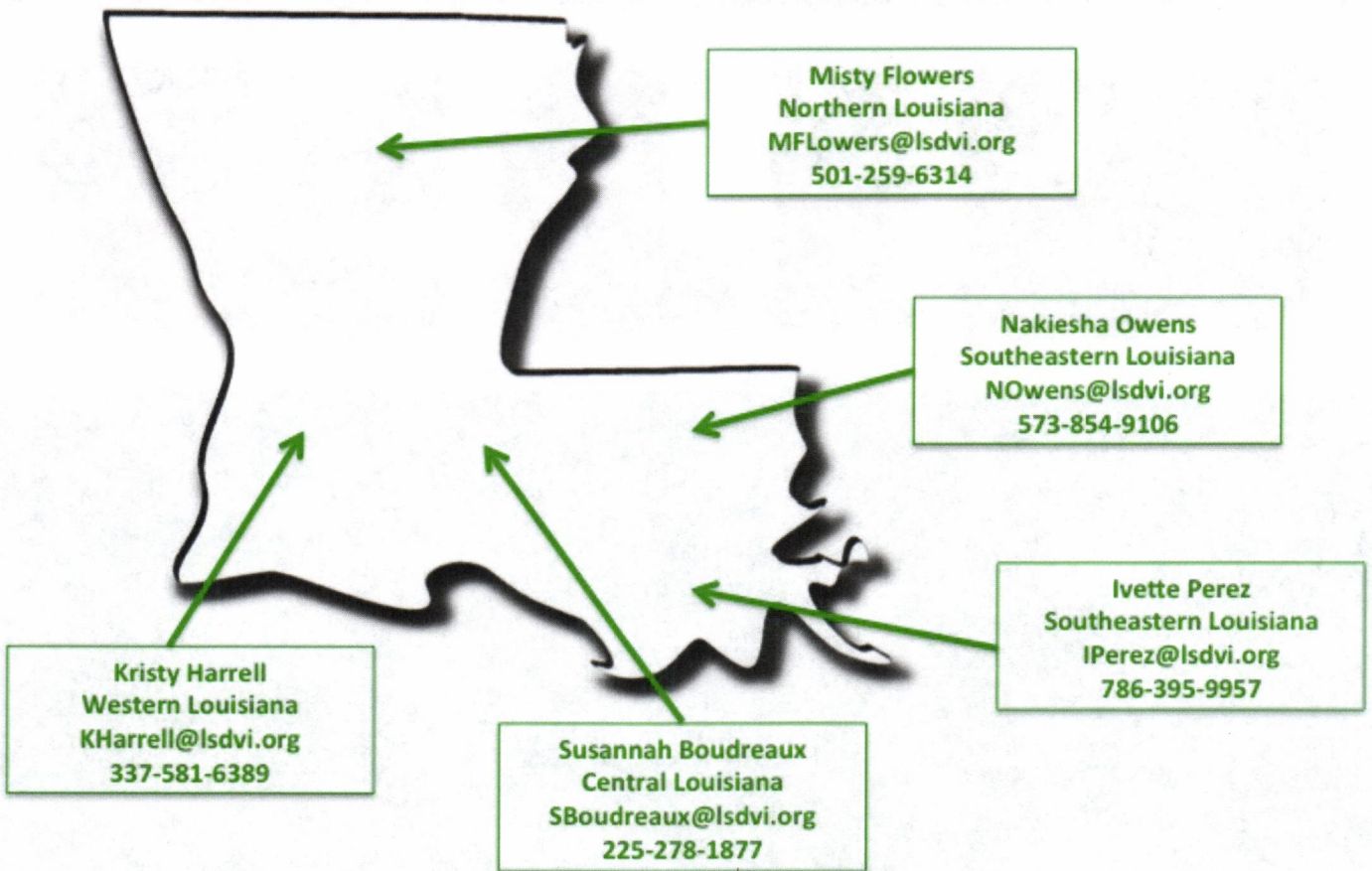
Program Services Include:

- *Visits from Teachers who specialize in the education of young children with hearing loss
- *Parent Education and Support
- *Support with Audiological visits
- * Speech and Language Development Monitoring and Coaching
- *Parent Networking Opportunities
- *Advocacy Support with IFSPs and IEPs

Referral for Services:
Susannah Boudreaux, Coordinator
SBoudreaux@lsdvi.org

Office: 225-278-1877
Fax: 225-757-3447

Parent Pupil Education Program Staff and Territories



Parent Pupil Education Program (PPEP) 2888 Brightside Dr. Baton Rouge, La 70820



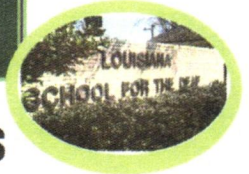
We are here to serve you!



Louisiana School for the Deaf

a Learning community that is **Student-oriented** and **Dedicated to excellence**

Established in 1852 providing 164 Years of Excellence in Deaf Education



Expanded Options for Deaf and Hard of Hearing Students



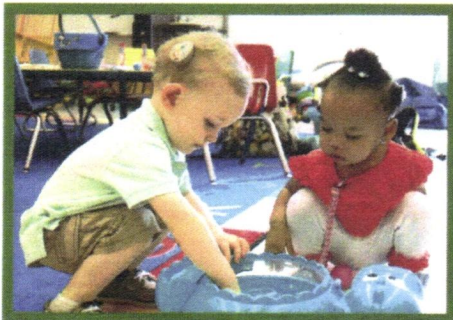
Amplification

Students will be encouraged to develop speech and language through listening with their hearing aids or cochlear implants.

Students' amplification will be worn during all waking hours at school.

Students' hearing technology will be tested every morning using the LING 6 sound test to ensure it is functioning properly.

An on staff audiologist is available to troubleshoot hearing technology.



Listening and Spoken Language Program

Starting in August 2017 at the Louisiana School for the Deaf, students can be enrolled in classrooms with certified teachers focusing on spoken language development through daily instruction.

Students will be provided with many opportunities to listen and talk in a variety of communicative contexts as well as participate in practice activities designed to improve their listening and spoken language skills.

Students will have dedicated speech instruction with certified speech language pathologists.

Students will have opportunities to learn and practice American Sign Language skills with their peers as well as adult language role models in the school.



Contact Us to Schedule a Tour

225-757-3202

**Louisiana School for the Deaf
2888 Brightside Lane
Baton Rouge, LA 70820**

MCHB - The purpose is to develop a comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) system of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, and early intervention (EI). This purpose will be achieved by focusing efforts on: 1) increasing health professionals' engagement within and knowledge of the EHDI system, 2) improving access to early intervention services and language acquisition, and 3) improving family engagement, partnership, and leadership within the EHDI programs and systems.

Year 1: 4/1/2017 – 3/30/2018

Goal/Aim 1: To increase health professionals' engagement within and knowledge of the EHDI system

Objective/Aim 1.1: By the end of March 2020, increase the number of newborns and infants who receive timely diagnosis by 30% of 2014 CDC EHDI HSFS baseline data (1.3%)*

Objective/Aim 1.2: By the end of March 2020, implement model for state-based learning community in two state regions.

Goal/Aim 2: To improve access to early intervention services and language acquisition

Objective/Aim 2.1: By the end of March 2020, increase the number of newborns and infants who receive timely referral to early intervention by 25% of 2014 CDC EHDI HSFS baseline data*.

Objective/Aim 2.2: By the end of March 2020, increase the number of newborns and infants identified to be deaf or hard of hearing enrolled in early intervention by 20% of 2014 CDC EHDI HSFS baseline data (56%).

Goal/Aim 3: To improve family engagement, partnership, and leadership within the EHDI programs and systems

Objective/Aim 3.1: By the end of March 2020, at least 75% of families will indicate satisfaction with their level of active family engagement partnerships.

Objective/Aim 3.2: By the end of March 2020, educate 100% of audiologists and physicians with a deaf or hard of hearing patient in their practice.

Attachment 3

CDC - Documentation and Use of Follow-up Diagnostic & Intervention Services Data through the Maintenance of the Early Hearing Detection & Intervention System

Year 1: 7/1/2017 – 6/30/2018

Strategy 1: Surveillance - To implement a complete state EHDI-IS that conforms to CDC EHDI functional standards

- 1.1 Maintain the Collection and Management of the Hearing Screening Data
- 1.2 Maintain Electronic Exchange Of Demographic Data Between EHDI-IS and Vital Records
- 1.3 Expand the EHDI-IS Capacity To Capture Diagnostic Data in a Timely Manner
- 1.4 Expand the EHDI-IS Capacity To Capture Early Intervention Data in a Timely Manner

Strategy 2: Training and Support

- 2.1 To provide training and technical assistance to address the needs of state partners involved in EHDI reporting processes. (e.g. audiologists, early intervention programs)
- 2.2 By June 30, 2017 increase documentation of diagnosis status after failed newborn hearing screening by at least 5% for 2016 birth cohort.

Strategy 3: Partnerships - To promote and support coordination and collaboration around sustained tracking and surveillance activities within the jurisdiction

- 3.1 To Promote and Support Coordination and Collaboration Around Capturing Diagnostic Data
- 3.2 To Promote and Support Coordination and Collaboration Around Capturing Early Intervention Data

Strategy 4: Strategic Communication & Dissemination - To support targeted dissemination of information among internal and external stakeholders

- 4.1. Submitting 100% of data to the National CDC EHDI Hearing Screening and Follow-up Survey (HSFS)
- 4.2 Support targeted dissemination of data and information among internal and external stakeholders to guide strategic actions and Increase EHDI-IS visibility
- 4.3 Use and Disseminate better detailed EHDI Individual data: (Expanded Activities)

Strategy 5: Monitoring, Analysis And Evaluation of the EHDI-IS - To Maintain Quality of the Data and Lead Strategic Actions for Program Improvement

- 5.1. Monitor Data
- 5.2. Analyze Data
- 5.3 Evaluate the EHDI-IS
- 5.4 Conduct Data Analysis to identify factors associated with LFU/LTD: (Expanded Activities)

Attachment 4