

## 01.25.19 EHDI Advisory Council Meeting Minutes

**Attendees:** Dr. Choojitarom (Dr. Choo) , Jimmy Gore, Melody Sparks, Jay Isch, Ariel Bumbala, Susannah Boudreaux, Danielle Mercer, Wendy Jumonville, Marbely Barahona, Melissa McConnell, Terri Ibeita, Theresa Nicholls, Jill Guidry, Nicole Deleon. Invited parents (Jill Gill, Olivia Lee),Invited guests: Andrea Outhuse and Chloe Lake.

Motion to accept last meeting minutes by Jay Isch, seconded by Melody Sparks.

### **EHDI Program Updates:**

Update from EHDI: Revising NB hearing screening form, public facing.

Loss to follow up discussion about families failing to follow-up or no documentation of their follow up. Continued efforts to reduce this number, changed system and protocol, contacting families more immediately; guided assistance from NICHQ, conducting PDSAs, reviewing data each month – calling families at 3 weeks and sending text to families – communication has been positive.

Hands and Voices, Guide By Your Side – hired 4 Deaf guides; a pilot is coming for a Deaf Mentor program; Terri and Dr Choo attended CMV conference; EHDI staff will be attending the national EHDI program in June. Dr Choo asked that all national EHDI conferences attendees meet following this meeting.

**Council Vacancies:** Pediatrician and Neonatologist – it's in the works. One parent on the Council has not attended a meeting; if missed more than two consecutive meetings they can be voted off – would need another recommendation of a family to join the Council.

Jay Isch made the motion to remove the parent off the Council, Jimmy Gore seconded. Voted unanimously, motion carries.

**Healthy Deaf Identity** (Jay Isch-PowerPoint Presentation). Below is a summation of what was discussed in this presentation and questions/comments made from the Council. The Deaf Community is a unique community, he was born into a Deaf family. Deaf adults shared that they are frustrated, growing up in hearing families. Many families feel hopeless and are not thriving in their communities. 90% of children who are deaf or hard of hearing are born to hearing parents. When a child is born deaf or hard of hearing he/she is born into both the hearing and Deaf worlds. In the hearing world, there is a dominant perspective on hearing loss, basically people want to fix or cure it. May want the child to read lips to communicate. We need both worlds. A child who is deaf or hard of hearing and has no communication system may feel isolated and have low self-esteem. It is important that all everyone encourages involvement in every part of the child's communication - signing, reading books, storytelling. Jay recommended that the early intervention classes that we had in 2008 that were similar to the preschool classes in Massachusetts. Additionally, these classes taught sign language to families and brought families together, which was important so that families could meet other families and Deaf adults in their communities. At present, not many children who are deaf or hard of hearing have these opportunities. Many children grow up in a negative environment and become depressed, anxious and/or introverted. Jay stated that a Deaf Mentor program would be helpful. Families who are Deaf deal with a lot of different doctors, most of which are hearing. They don't have many professional or language models who are Deaf. We want to provide opportunities to meet others who are Deaf. At Gallaudet University, they are partnering with the Deaf Education Center at Boston's Children's Hospital and have established

classes for families with children who are deaf to promote their Deaf identity. Jimmy Gore stated that many students enter the University as young adults and they begin to feel angry and frustrated, trying to find themselves. Many are not facing this until they are much older and if we started working on a positive Deaf identity earlier, it could help them feel more confident and well adjusted. Marbely stated that as a parent, it is important for her son to have healthy Deaf identity. It was important to her that he knew he was Deaf and he had access to oral communication. She stated that as Guide, working with a family whose baby is deaf, it does not really matter what mode of communication the family is using. Their focus is loving their baby, exactly how he or she is. Marbely shared her excitement about the Deaf Mentor program and said she needed that as a parent. Additionally she said that LSD can't fix everything and that families should have access to resources, even those who do not live in Baton Rouge. Families may want to learn sign language, yet many don't have access to classes; LSD should reach out to other areas of the state that need access to sign language classes. In some areas of the state, there are minimal to no resources available. Deaf Mentors could help with this, they could be going in the home and helping families learn ASL each week. Families could learn a lot. We need to do something and invest more in these types of programs. Susannah mentioned a program called Sign It by Racheal Coleman and stated that many families are frustrated with it because it is not the same as having a one-on-one conversation with another person. Additionally, there are different accents in ASL, families will become more familiar with this, as they get to know their Deaf community. The support provided to families should be individualized, Deaf Mentors can assist with reducing negative bias and increasing access to different communication modes and meeting others who are Deaf. She recommended that LAD be more involved with families. Need to do something different. LDE and LDH will work better together at the state level through the LEAD-K legislation. Deaf Mentors will also support the employment of individuals who are Deaf or hard of hearing. Jimmy stated that families with children who are deaf need a sense of community, even if they do not use ASL. Dr. Choo asked about the partnership between Gallaudet and Boston's Children's Hospital and the Parent-Infant Program at the Laurent Claire School for the Deaf.

**LEAD K:** Susannah provided an overview and update on the LEAD-K Taskforce: 6 meetings, July 2018 to January 2019. Reviewed five charges from the legislation. The Taskforce report is due in February 2019. Primary charges: track language development and outcomes for children who are deaf or hard of hearing and recommended changes to our system for young children. Jay stated he was looking forward to the recommendations what change will happen for kids, as there is bias and language deprivation. Melinda asked to share some of the recommendations (existing tools to track language and literacy development; SKI-HI to track receptive and expressive language development; anticipated collaboration with EarlySteps and EHDI related to data collection; data collected at a minimum of every 6 months; more data collected by individual providers; Task Force will develop language milestone tools, both in ASL and English; State should have a robust data system with many different data variables, like when the child was identified with a hearing loss; type and degree of the hearing loss; families' native language; progress toward language milestones; preferred language of choice and mode of communication; final recommendations are pending. Melody asked who would be responsible for entering data and tracking progress. LDH and LDE will provide written responses to the Taskforce report in March 2019. Melody asked about delaying the submission of the Taskforce report to the legislators, Susannah stated that the report will be submitted before or on the expected due date.

**Hands and Voices update** (Jill and Nicole): Shared information about the Program and disseminated updated program information. Information will be printed on a card to share with families, including

community events for all families, even those not associated with the Program. Jill passed out brochures and Nicole shared the website information about upcoming events. Stated that the Program is working more closely with PPEP, will sponsor upcoming PPEP events at LSD. Currently have 4 guides who are deaf or hard of hearing, plan to add 2 more to the Monroe and New Orleans area. Guides work together to cover areas statewide. This set up is similar to PPEP and ES, providers that cross regions. Dr. Choo asked about the next fundraiser. The event will be at Rock N Bowl in Lafayette – parent guide is reaching out to them in Lafayette. Guides are meeting February 8, including PPEP staff for a training and to discuss fund raising. Also mentioned that all guides have a mandatory annual face to face training each year. Sometimes twice a year; typically use a Zoom platform to connect. Guides are part-time.

**NHS Form Update:** Terri led the conversation about the hearing screening form. They are in triplicate form, doctors receive tip form that includes information about risk indicators for hearing loss and what type of diagnostic evaluation. Parent sees the pink form. Discussion about including the “What parents need to know form” on the back of the pink form. Recommended changes focus on identification and communication development – get services they need as early as possible. Want message to come through in these forms. Tag line: early communication is key will be threaded throughout forms, messaging. Form sent through Google Documents – can send feedback that way too.

CIA team mentioned work toward the form, meeting every week – dissecting the language. Trying to capture all points of view. Would love to hear from council and parents.

Parents (Olivia and Jill): language comes across as more family friendly versus the old document where the language was very scary, less positive. Jill stated that her son’s hearing was not addressed until follow-up, thought it was fluid in his ears. Need education for hospital staff, in addition to the changing the forms. Melody asked a question about who shares results with families, younger audiologists? Jill stated that her son is profoundly deaf and said his hearing loss was not detected with screening, his hearing was screened twice in the room. Terri and Wendy spoke to who does the screening in the hospitals; out of 50 birthing hospitals, about 20 are outsourcing with 3 main companies. Most screen the baby’s hearing in mom’s room and provide results to the families. Typically well trained, we provide education and scripts. Remainder of hospitals, the hearing screening supervisor will hire techs; most screenings occur in nursery; other hospitals, the nurse conducts the screening. Every hospital has a hearing screening supervisor – audiologist or MD. Jay recommended that EHDI should try to do sensitivity training for all nurses in the hospital. Terri stated that maybe they could have a recorded, video training that they would have to watch, then submit documentation for the training. Wendy stated that there should be training for every person who is conducting screening, not just nurses. Jimmy asked if there was a video available, recommended to review what is out there before developing it. Ariel responded to the comments and suggested that the primary approach should be a face to face training. Video may dehumanize the training. Terri stated that EHDI does do hospital visits at different times for different reasons. Could be done, target who needs additional training. 100 babies identified, prioritize hospitals that most of these babies come from; Wendy stated that they use a national training curriculum. Dr. Choo commented that hearing screening is important for language development, 2<sup>nd</sup> bullet on form...”need to receive services before 6-months” should not wait until 6 months, should be as soon as possible. National guidelines of 1, 3 and 6. Teresa Nichols commented that the form says 6 months, literature should back up our recommendation. Research did not say 3 or 6 months, but for children receiving EI...focus on 6 months. Melissa suggested that the NHS training, even if recorded, could be humanized, if given by a parent who is deaf. More emotional connection is needed. Jay

suggested that we be more specific about development, to add “cognitive”. Chloe and Andrea responded, stating that it should be written in a way that all families understand it. Tossed around early childhood and/or cognitive development, which may not be easily understood by families. Gina and Susannah suggested to bring together a group of families and get their input to figure out the best language to use. Additional recommendations were to keep it simple and to the point, to not overwhelm families with too much information. Someone recommended “mental” as a substitute word for cognitive, many did not like this, as sometimes this is associated with a learning disability. Ariel stated that this is something that the Deaf Mentors could help with, families could ask them to help find out more information about a topic, problem solve, etc.... Stated that we had to remember that we need to be positive and supportive of families. Must capture their heart and attention to help them understand what it may be like for them to raise a child who is deaf. Talked about convening a focus group with a diverse mixture of parents. This form will be provided to all families. Suggested having more one-pagers, visuals related to screening, rescreening and early identification. Marbely suggested that families may need more explanation as to why they need to return for a rescreening. The group talked a bit more about using the word “cognitive”. Gina suggested using something like it is important to “help your child grow and learn” “. Feedback on form: important to help your child learn and grow. Chloe and Andrea recommended using a survey tool will families to capture what they like, don’t like, what is hard to understand, and does not make sense. Get feedback from everyone; parents with and without children who are deaf or hard of hearing. Terri Ibieta provided a numbers example: out of 500 babies, 480 will pass NB screening. 20 will require rescreening and one of them will be identified. 4% rescreened 1/3000-4000 will be diagnosed. Jimmy Gore commented that the form was too difficult to read. Not best copy – maybe change colors. Need to think about sustainable costs for color printing.

**CMV Presentation:** Bullet points (highlights) from Dr. Choo’s presentation. He and Terri attended the CMV Conference, September 2018 Cytomegalovirus, LA Hearing Chapter Champion, AAP

- CMV known for a long time, we thought it only affected very small babies and those undergoing organ transplant. Tricky virus, difficult to identify and treat – PH Challenge
- It’s a virus, not a bacteria, requires a host cell – usually humans. Has extra protein. Transmission: saliva, se, placental transfer, breast feeding, blood transfusion, organ transplant
- PH: seroprevalence – percentage of population with particular infections, certain population (60% or more) has had CMV. Seroconversions – rate a person changes form undetectable levels to pathogen to detectable leave
- Childcare providers convert at high rate, same with parents. Life cycle, infection – penetrates tissues, will highjack cellular mechanism to reproduce over and over or it can hide/incorporate self into host cell on DNA in own body and as our cells multiple, so does the virus
- CMV like the flu, maybe mono-like – gets more serious if pregnant, virus can be passed to fetus. Or a solid organ transplant on immunosuppressant drugs. Immunology: important how CMV is detected. Body has multiple defenses: CMV counter measures: variability of molecular patterns, through prior exposure is protective, decoy proteins. Not gotten rid of CMV, still there. If defense mechanisms not intact, don’t have one – newborns don’t have immune system. Small percent of NB have CMV due to moms, in intensive care unit – take care of symptomatic CMV – brain abnormalities, eye, recognizable rash, problems with spleen; asymptomatic – how do you tell risk factors? Guideline (provided in handout) in 2015, great set of recommendations to make a classification – severe CMV, symptomatic, mild symptomatic CMV and asymptomatic CMV.

Likes white blood cells, kidneys (you tube reference of immune system). Take a test to detect CMV. This is just a slice in time of a dynamic thing in the body. If you do a test early after contamination (detects IgM), you may detect something. Later, you would detect other hemoglobins/immunoglobins. (Detects IgM and IgG).

- PCR amplifies tiny amount of CMV virus in the body is magnified. Very expensive and difficult to do.
- Greatest risk, mom never had infection, gets infection in pregnancy, high rate of transfer to the infant. Pre-exposed may not be as protective – passive immunity is not perfect.
- 4 million births, 40K with CMS. Maternal primary infection, 4000 with symptomatic CMV – 90% have neurological problems, smaller percent have asymptomatic = 36K, 14% neurological – sensorineural hearing loss.
- Researcher in Brazil, 12K – 30% of hearing loss was caused by CMV.
- How do we identify and prevent? Time is important. Recommendations do not recommend routine screening or intervention, no clear evidence that this helps. Many moving toward vaccination and prevention. Numerous vaccines being tested. Prevention: we know risk factors, can do a better job of informing pregnant women and inform providers about CMV> Newborn screening (lots of tests) CMV detected in saliva and urine, maybe blood. Testing must be done before 3 weeks, after that can't distinguish between congenital versus inflectional CMV. Not really thing in place for saliva. Do have infrastructure for dried blood spot test – why not put CMV test in dried blood spot, don't know if that works yet. DB spot – recommended universal screening panel. Unfortunately, we can't detect if accurately and cumbersome to add test to universal screening panel. Even if approved by HHS Secretary, its encouraged but not mandatory. Treatment: medication ganciclovir, valganciclovir – testing has not yielded major results. Some improvement at 24 months. Significant side effects. No difference in hearing after treatment, neurodevelopmental testing, and some improvements in development – was not statistically different in relation to hearing.
- Approximately, 14% of children with SN hearing loss; another study suggested that 30% of hearing loss is caused by CMV. This a PH concern that needs to be addressed. CMV always not diagnosed early.
- Summary: popular virus, not understood. Detection is an issue, clinically and PH perspective, treatment is a problem; not a lot of solid data that treatment works. Take-away: prevention of CMV disease + vaccination; should begin early intervention earlier versus intervening with meds. At least 9 states have legislation around CMV. CA and Maine putting together a task force to investigate congenital CMV.
- Resources: National CMV Foundation
- NB screening panel: 35 tests – reduce morbidity, mortality and is cost effective. Differs among states, this is a recommendation – LA tests for 28, TX tests for much more.
- Prevention begins with awareness, need to improve this with pregnant families. No one knows about this. How do we help teach this and to prevent (universal precaution). Most susceptible, first trimester of pregnancy.
- BFH, target pre-pregnant and pregnant moms. National organizations tend to educate and send health recommendations to parents. Not to duplicate efforts in National Campaigns.....At least 9 states that have funded awareness programs....campaign – geared toward women who could become pregnant and OBs...

**Additional Updates:** Susannah stated that they were updating the LA EHDl website, and by the next meeting it should be live with revisions. Melody Sparks provided update to the group about the DEA conference on February 1-2 in BR, Holiday Inn South. “The Earlier the Better” – conversations about early language development. Presenter talking about neurodiversity and deafness; parent panel, expert panel to discuss language and early identification. Presenter from Kansas school for the deaf to talk about EI, ECE and family involvement with 3 different breakout sessions; visual language; LEAD-K update; Dr. Choo and Susannah will be part of an expert panel; deaf actor – stand-up comedian. Look at Deaf Focus website for more information. Jimmy added that this was an opportunity to better understand Deaf Culture. Options available for schools, actor will talk to children. CJ (actor) is very inspirational.

Next meeting date: April 12, 2019, 12pm- will be in Bienville Building

Future dates: July 26 and October 25, 2019

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