

# **UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE**

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*Next Meeting  
February 12, 2013*

November 13, 2012, meeting minutes

In attendance: Krysta Badger, Susie Bohning, Kelly Dick, Susan Fox, Rich Harward, Catherine Hoelscher, Nita Jensen, Katie Jolma, Stephanie McVicar, Karen Munoz, Taunya Paxton, Lori Ruth, Suzanne Smith, Sharon Strong, Jill Vicory, Karl White, Sylvia White, Shannon Wnek, Jennifer Bryant – Guest, Jill Boettger - Guest

Absent – Charlene Frail-McGeever, Albert Park, Kathleen Pitcher-Tobey, Paula Pittman, Harper Randall, Kurt Randall

## ***WELCOME***

Dr. Kelly Dick opened the meeting at 9:10 am. Members as listed above were excused from today's meeting. New committee member, Catherine Hoelscher from Baby Watch, was welcomed. Catherine replaces Vanya Tanner on this committee as a representative for Baby Watch Early Intervention (EI). She has a Master's Degree in Public Health and has worked with the Baby Watch program for the last 6 + years. She currently oversees fifteen agencies that provide EI services and is also involved in Child Find. Paula Pittman, the new USDB Parent Infant Program-Deaf Director was committee approved to replace Day Mullings, although she was unable to be in attendance today. Lori Ruth will also continue to attend as a consultant of this committee.

A motion was requested to approve the August minutes. The motion carried with all in favor and with no one abstaining.

## ***Public Comment***

No comments.

## ***Vote Items***

Vote item: Catherine Hoelscher was presented as a member of this committee representing Baby Watch early Intervention, a mandated seat noted in Utah Code 26-10-6. The motion carried with all in favor and with no one abstaining. Vote item: Paula Pittman as a consultant member of this committee representing the USDB Parent Infant Program-Deaf. The motion carried with all in favor and with no one abstaining. Vote item for Lori Ruth as a new consultant position on this committee representing PIP Parent Advisor Consultant. The motion carried with all in favor and with no one abstaining. (Voting members in attendance at the time of the vote: Krysta Badger, Susie Bohning, Kelly Dick, Susan Fox, Rich Harward, Nita Jensen, Katie Jolma, Stephanie McVicar, Karen Munoz, Taunya Paxton, Lori Ruth, Suzanne Smith, Sharon Strong, Karl White, Sylvia White, Shannon Wnek.)

## ***Utah EHDI Updates***

The annual Utah EHDI Conference was held on September 30<sup>th</sup>. There were 29 attendees and \_\_\_ hospitals represented. Wendy Chatland, the Newborn Hearing Screening Coordinator from Fillmore Community Hospital and parent of a deaf daughter spoke about her perspectives and experiences. Her daughter was born without auditory nerves and uses cued speech as her communication method. Wendy showed us how cued speech works. Debbie Eskelson from HiTrack presented tricks and tips for using HiTrack. Krysta Badger spoke on loss to follow-up efforts through state EHDI. Breakout sessions included hands on HiTrack training and Audiology Best Practice Protocols. Having many hospital supervising audiologists in the same room to work on protocols was exciting. Audiologists were invited to bring ABR waveforms they found hard to interpret and a panel of

pediatric audiologists discussed and helped interpret the wave forms. This is something we would like to do again; it was very helpful to have input from other professionals. Dr. Katie Jolma, EHDI Chapter Champion, was also on the agenda, although she could not attend in person. Kurt created a video presentation on Dr. Jolma's perspectives from the pediatrician/medical home and the best way to communicate a diagnosis of a child with hearing loss. This presentation was very highly valued. Dr. Albert Park also presented on the role of the Pediatric Otolaryngologist. He presented research regarding what directs the ENT on their next steps. As Audiologists refer to the ENT, but do not always know what happens next with the child.

The CDC cooperative agreement site visit was held in Salt Lake on October 15<sup>th</sup> and 16<sup>th</sup>. Mountain states with CDC funding (Arizona, Idaho, Montana, Colorado, Utah, Nevada, Wyoming, New Mexico) participated. We met with Utah liaisons, Claudia Gaffney and John Eichwald. Carryover funding requests will be very difficult now as CDC has moved more to a "use it or lose it" tactic. We were also told that sequestration would be happening across the board on January 1, 2013. This will include cuts to federal programs that could be devastating to EDHI funding for UDOH - both CDC EHDI and HRSA. EHDI Pals, a national on-line guide to pediatric audiologists that launched last week was introduced. Karen Munoz will present this in more detail at our next committee meeting. This is a resource for parents/professionals to find pediatric audiologists in their area. Since its roll out, there have been over 250 applicants. The possibility of creating an inter-jurisdictional data sharing agreement to allow border states to share newborn hearing screening information was also discussed. John said he would look into this further.

We are still working on the Tele-audiology pilot project. Dr. Stephanie McVicar, Dr. Shannon Wnek, and Kurt Randall have tested seven children so far (the pilot goal is ten). They have discovered that if the child has any type of suspected hearing loss, the Vivosonic diagnostic equipment only works reliably if the child is sound asleep. If a child's hearing is normal, the waves can be interpreted easily, but if the child has any type of hearing loss and is not completely asleep when tested, the waves are very difficult to read. This is similar when testing by tele-audiology or in person. The midwife on this project, Michele Thompson, is going to start using a Verizon hotspot to help reduce internet connection issues. This pilot project is very helpful in "working out the kinks". We are also part of a nationwide workgroup, led by NCHAM's Diane Behl, that is piloting tele-audiology across the US. Charlene Frail-McGeever is also part of this workgroup and, on their call last week, she spoke about how Medicaid views tele-health and what we can do to get these sessions covered. Colorado noted that audiologists are not recognized as tele-health providers. We need to pool our efforts and lobby for tele-health to cover audiologist providers by proving that it is cost effective and just as reliable as an in-person visit. The federal government must agree that audiologists can be telehealth providers before Medicaid can address coverage. Taunya Paxton noted that insurance still won't pay for Chance's audiology/programming visits as they are considered cosmetic. We have a long way to go. Our main purpose with the tele-audiology pilot is to reduce the loss to follow up rate for rural children. In that last few months, Representative Rhonda Menlove has contacted Harper and CSHCN audiology about an interest in hearing loss and will hopefully be an ally in getting hearing aid coverage mandated in Utah.

With Dr. Harper Randall's encouragement, Dr. McVicar submitted a presentation proposal for tele-audiology to AMCHP (Association of Maternal and Child Health Programs). It was approved and will be presented at the annual conference, February 11, 2013. Dr. McVicar has also submitted an abstract of this to the National EHDI conference to be held in April.

Dr. Jay Hall will be presenting at a special Utah EHDI conference on May 2 & 3, 2013, hosted by Utah EHDI, at little or no cost for Utah audiologists. Dr. Hall was one of the guest speakers at the Amplification for Infants and Toddlers Conference in Idaho, June 2012.

Kurt and Nita Jensen conducted eight hospital site visits in Southern Utah in September. This included Kane County Hospital in Kanab (no previous visit) who has a new screening coordinator, Charlene Kelly, just transferred from Dixie to replace the retiring coordinator. All Utah hospitals are working towards upgrading to web-enabled Hi-Track; eight hospitals already connected and on-line. Hildale Maternity Home's birthing center has closed as they are not having many births. Screening services are available in that area still, as there is a sound booth in Colorado City as well as a Hearing Specialist Nurse who oversees screening and hearing aid needs of the older kids in the area. Stefani Watson, USDB audiologist, also travels to that area. The hospital reports included in today's handouts show data through the end of September; the yellow entries on the report card are part of the home birth hearing project and the only ones not reporting in Hi-Track (data is entered by hand). Any questions on data please ask Nita.

### ***JCIH OAE and AABR, ABR Recommendations***

Dr. Kelly Dick has had some recent concerns from nursing staff regarding the necessity of testing infants for both OAE and AABR as parents are billed for both tests. He briefly explained the role of the Joint Committee on Infant Hearing (JCIH) as well as what hearing systems are addressed with otoacoustic emissions and automated brainstem response. This is mainly a concern for NICU babies, as national NICU screening recommendations outline when both tests are indicated. Dr. Richard Harward asked if this could be a DRG issue with the birth of the baby (Diagnostic Related Group: when a child is born there are certain procedures "bundled" into one billing code). The initial screen is normally included in the DRG. Sylvia White asked if AABR is done only following failed OAE. That really depends. A hospital with a two-stage screening does AABR following failed OAE so the screening is complete at the time of discharge (decreasing the possibility of loss to follow-up). The issue at hand for this discussion is NICU screening protocol, and billing for two separate hearing screening procedures for every baby in NICU > 5 days. Dr. Karl White noted that the JCIH recommends that an ABR be done for babies in the NICU and most hospitals that do an AABR in the NICU also do OAEs; he is not sure if JCIH is clear on that. Dr. White thinks an appropriate response to questions would be that we are following the JCIH protocol and whether we agree or not, that protocol is endorsed by the CDC, the AAP, and other organizations. To not follow the JCIH recommendation for NICU babies would be risky. Dr. Harward's response is that we are testing for two different things, cochlear vs. neuro-pathway, and there are situations where it is clinically appropriate to do both. Dr. Dick has had this conversation with Neonatologists and they agree that both tests be completed. The best response is to cite JCIH recommendations. Susan Fox noted that nursing staff may be hearing about billing changes for NICU patients and are concerned for the family. It might be that nurses don't understand that we are testing for two different things: OAE tests the outer and middle ear function of hair cells that line the cochlea (only peripheral system); while the AABR/ABR tests neural function, a risk to be considered for NICU babies. NICU babies will often pass OAE because their sensory system is normal, but will not pass the AABR (the neural system). It is helpful in these babies to document if they pass one and not the other, and then re-asses the system not passing. Karen Munoz looked up the JCIH position statement:

"The 2007 JCIH position statement includes neonates at risk of having neural hearing loss (auditory neuropathy/auditory dyssynchrony) in the target population to be identified in the NICU,[55-57](#) because there is evidence that neural hearing loss results in adverse communication outcomes.[22-50](#) Consequently, the JCIH recommends ABR technology as the only appropriate screening technique for use in the NICU. For infants who do not pass automated ABR testing in the NICU, referral should be made directly to an audiologist for rescreening and, when indicated, comprehensive evaluation, including diagnostic ABR testing, rather than for general outpatient rescreening."

While the statement does not say that both technologies need to be used; by using the OAE you will also be testing that the sensory system is working, not just neural. This point has long been discussed/argued within

JCIH. From a liability perspective, all hospitals should refer to this position statement. If someone is suggesting that we shouldn't be doing AABR in the NICU, the JCIH statement addresses it. This may be an issue of the staff not wanting to do both tests as an advocate for the parent. It would be useful to have data showing if the insurance is not paying for both tests, but Dr. Harward noted that the UDOH seldom gets calls from parents regarding hearing screening billing. Also to note is that the AABR is not much more expensive than the OAE. It is the diagnostic ABR that gets expensive. There will be a charge for each test, but if it is under a DRG, it is a moot point. A NICU baby can cost \$750,000, so ABR test costs are miniscule compared to everything else on an NICU billing. For a well-baby, Susan Fox doesn't think the NICU has DRG bundled billing.

Dr. Susie Bohning explains to parents, if they are present in the NICU, what she is doing while testing the baby, and why each test is warranted. New nurses are also oriented to the testing and why it is done. This is a matter of education and Dr. Bohning's approach is a good one. Dr. White believes the message is to continue to educate. If nurses don't understand, if physicians don't understand, as a committee we need to continue to encourage hospitals to educate on protocols, etc. Dr. Dick feels the hospital staff do not always understand that both tests may be clinically warranted. There is an ongoing committee that will soon make recommendations on NICU levels, at that time we will discuss what levels will need AABR. Susan will take this information back to the NICU managers; she and Kelly will discuss the issues. We need to continue to educate; there will be an opportunity because of the new NICU changes coming. Dr. Harward will continue to update this committee on those changes.

### ***National EHDI Updates***

The next National EHDI Conference will be held in Phoenix, Arizona on April 14-16, 2013. Notifications will be sent out by the end of this week for accepted abstracts. They had 20% more proposals this year (230), with only room for 180 presentations. There will be nine pre-sessions on Saturday and Sunday prior to the meeting. Last year there were 500 attendees at the pre-sessions and 1000 attendees to the actual conference. One of the most important aspects of the conference, to Dr. White, is the state stakeholder's meeting where everyone from the state brainstorms together.

At our August meeting, Dr. Karl White reported the results of the Utah pilot of NCHAM's Physician's Survey. Results were not as encouraging as hoped and showed that more education is needed. Around 30 states that will be replicating this survey – summaries will be provided at upcoming committee meetings. Karl would also like to complement the state on the tele-audiology project. This has been talked about for 20 years and, until this pilot, nothing has really happened.

### ***Family to Family Support***

Taunya Paxton has been researching how other states fund parent support programs. She is still working on compiling information and will present her findings at our next meeting. She has found that Colorado uses grants along with EDHI and state funding, justified because it helps newborn hearing screening. They also use Hands & Voices funding and have about nine employee parents. Hands & Voices is very strong there. Taunya will write up her findings and send to the committee so we can review sources and processes. Dr. White suggested that the most successful parent support programs come from states who have money to do it and, like Minnesota, went to the legislature for support. Colorado and Indiana have done the same. We don't know how the next funding year is shaping up (legislatively) with the fiscal cliff, but in terms of tax revenue, there was "new program" tax money last year. Dr. White is optimistic that this year may be the year that we could get \$30,000 to initiate a structured parent support program. Funding would make a huge difference. He knows that Representative Rhonda Menlove has a personal interest right now in hearing loss and she might be approachable. She is particularly interested in CMV and was very supportive of the hearing loss appropriation funded six years ago. What we have learned about successful legislation with the initial newborn hearing

mandate was the importance of finding a legislator who has a personal interest. Craig Peterson had a daughter with hearing loss and was in a position to help at that time. Dr. White thinks that with the current potential legislator interest, we may want to put together a proposal for funding. It would be best if a parent group could put together this proposal for an appropriation (Lisa Kovacs from Indiana and MaryEllen Bondhus from Minnesota may be able to provide helpful input); a proposal is a lot of work with an unknown outcome. The UDOH cannot help with this, but AG Bell and other existing parent support groups can. This is mainly about awareness, what hearing loss affects and getting legislators to see the costs associated with hearing loss and education if not addressed early. In Indiana, Minnesota, and North Carolina, parent-driven actions helped secure funding. North Carolina's Beginnings program has a line item in the legislated budget that details how the funds will be used. They are independent and that is extremely important. States with independent advocates/advocate groups have been more successful (not running through the health or education departments). Dr. Harward thinks this would be the appropriate approach. The advocacy issues could still work, and could be tiered with some other issues. People don't seem to understand the early intervention needs with hearing loss with the same urgency like they do with autism. Dr. Harward noted that the autism study going on now is somewhat of a rebound issue of the state not wanting to mandate services. Medicaid, PEHP, and the Autism Treatment Fund are paying for services through this study, enacted because of vocal parents. While the School for the Deaf has made great progress in incorporating different modalities and is an incredible resource for families, getting a small legislature appropriation would be a better shot for a parent group. The total budget for USDB is 21 million and it is a big organization. To add \$30,000 to that budget would have less impact than getting a parent group who would coordinate with USDB. Dr. Harward mentioned that we have taken steps backwards on some issues (i.e., Guide By Your Side) because of the Medicaid breach and increased security issues. One of the nice things about approaching this legislatively is that legislation may resolve some of those issues (can't do away with privacy). This approach pushes support entities into the domain of family advocacy rather than State program "ownership". Dr. Dick knows a senator who has children with hearing loss who may be willing to address these issues in the Utah Senate. Dr. McVicar and Dr. Harward are meeting next week with Rep. Menlove to discuss hearing/hearing aid issues. Taunya and Lori will meet (preferably before the first of the year) and talk about what family associations could contribute to the proposal. There are willing people; sometimes it's tough to know where to begin. Rep. Melvin R. Brown is chair of the Appropriations Committee. He is very pro-children; very supportive of early intervention and children in general and may be a good resource. Rep. Lyle Hillyard, in Cache Valley, has been supportive in the past. These people would be great resources, but may not carry the torch directly. Taunya and Dr. White will talk after this meeting for further action steps.

### ***Required Public Meeting Training – Lyle Odendahl***

Lyle Odendahl, with the Office of the Attorney General, is here today for the annual required public meeting training. He distributed a copy of the 2011 Act for Open and Public Meetings as well as a copy of his speaking notes. He noted that government works best when transparent and people know what is going on: "Government in the sunshine". A Public Meeting requires a public body (created by statute, rule, or ordinance) and has some type of authority or is supported by public funds convening for the purpose of taking care of business. This is a "public body". Utah Code 26-10-6 and Rule 398-2 bring this group together. There are ELEVEN mandated members for this group with additional members appointed. There are currently 22 seats on the committee (four staff members, seven consultants, plus the eleven mandated members); all additional seats were approved by committee majority and serve to support newborn hearing screening programs and policies. There must be 12 members at any meeting to have a quorum (majority); details are noted in approved committee By-laws. All meetings must be published on a public notice website and/or the press must be notified. The agenda must be somewhat specific (enough so the public can know what is being discussed and decide if they want to attend) and must give a date, time and location. If something comes up during the meeting that is not on the agenda, at the discretion of the Chair, you are allowed to discuss the subject, but no final action can be taken. Any meeting

for which you cannot give 24 hours' notice is considered an emergency meeting and the Assistant Attorney should be contacted as specific requirements must be met to convene an emergency meeting. This is the same for a closed meeting (which may only be held for certain circumstances, see handout). Written minutes must be available to the public within a reasonable time, recorded audio minutes within 3 days. These must be labeled and must have the substance of everything that is discussed. Each time there is a vote, the vote of each individual member must be recorded, with each individual listed. You can record the vote as unanimous without listing names or just list the names of those abstaining. You must record the name of each guest that speaks and the substance of what they speak about. If someone wants to submit any documents to the record, you must accept those from any committee member. There must be a mechanism in place to review and approve minutes. An Electronic Meeting occurs anytime a member of the committee calls in or you communicate with a member of the committee electronically. There must be advanced notice for an electronic meeting to occur. There is a department rule in place governing electronic meetings. Use good judgment and discretion if texting, but don't try to get around open meeting rules with text messages. All votes must be taken during the meeting; votes cannot be taken over email. An open meeting is not a meeting for the public to speak; it is open for the public to observe. However, it is wise that if someone from the public attends and has something to say that is meaningful and to the issue, and you have time, you should allow them to speak. This should be recorded. It is a class B misdemeanor for openly violating the Open Meetings Act, or aiding and abetting someone else's violation. Recorded and written minutes must be retained in or converted to a format that meets long term storage requirements. We might want to see if we have a retention schedule with archives, as we currently save recordings on tape, not digitally. It is a good idea to get a digital recorder.

### ***New Business***

Legislative update will be provided at the next meeting, to be held February 12, 2013. Eric Smith, a parent presenter for legislated hearing aid coverage (from last year) has not been in contact with Karl. He will be contacted early in 2013 to see if he is working with a legislator in 2013 on pediatric hearing aid coverage.

Adjourned by Kelly at 11:05, vote to adjourn by Karl, seconded by Sylvia.

**Advisory meeting schedule for 2013:** February 12, May 14, August 13, and November 12. All meetings will be held from 9-11am at the Utah Dept of Health, CSHCN Building , 44 Mario Capecchi Dr, SLC, Conference Rooms C-D.

**FYI**—You may subscribe to notices regarding this Committee on the Utah Public Notice website with instructions at <http://pmn.utah.gov> . Agendas will also be posted on that website at least 24 hours prior to the scheduled meeting.