UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

Next Meeting
November 13, 2012

August 14, 2012, meeting minutes

In attendance: Krysta Behring, Candy Bleazard – CSHCN, guest, Charlene Frail-McGeever, Rich Harward, Nita Jensen, Katie Jolma, Karen Munoz, Harper Randall, Kurt Randall, Lori Ruth- USDB, guest, Suzanne Smith, Vanya Tanner, Michele Thompson, Midwife-guest, Karl White, Sylvia White

Absent – Susie Bohning, Kelly Dick, Susan Fox, Stephanie McVicar, Albert Park, Taunya Paxton, Sharon Strong, Jill Vicory, Kathleen Pitcher-Tobey, Shannon Wnek

WELCOME
Dr. Richard Harward opened the meeting at 9:10. Members as listed above were excused from today's meeting. A motion was requested to approve the May 8th minutes. The motion carried with all in favor and with no one abstaining.

Introductions were made. Dr. Harward has accepted the position of Bureau Director for Children with Special Healthcare Needs (CSHCN). His position as EHDI Program Manager has been filled by Dr. Stephanie McVicar, AuD. Dr. McVicar has worked with CSHCN Hearing & Speech Services as an audiologists for the last five + years, and is a current "staff" member of this committee. Dr. Harward will continue to be a voting member of this committee.

Dr. Katie Jolma is the new AAP EHDI Chapter Champion. Dr. Jolma has been a General Pediatrician since 2000. She has worked with the CSHCN clinics doing development assessments in past years. She has completed URLEND training and now works for a private practice. Dr. Jolma is part of the Medical Home project, creating Medical Home website modules on hearing impairment, Turner Syndrome, autism, and Down Syndrome (www.medicalhomeportal.org). Dr. Jolma has a child with autism. We are thrilled to have Dr. Jolma as part of our team representing Utah EHDI. Dr. Karl White will send Katie the new NCHAM training CD to accompany her AAP Chapter Champion training/resource notebook.

Suzanne Smith, licensed direct entry midwife, (LLC, Better Birth/Bella Natal), has also joined this committee. Prior to 2008, the home birth screening rate in Utah was 9%, and efforts began to focus on increasing screening/reporting hearing for this population. Suzanne was the first midwife enrolled with the Homebirth Hearing Screening project. The out of hospital screening rate has increased from 9% to over 70% (see handout for statistics). Because of the success of this project, we felt a midwife should sit on this advisory committee. There are a few other states that have a midwife on their Advisory Boards. Nationally, about 2% of all babies are born outside of the hospital. That is very significant: 80,000 births a year. Suzanne started in midwifery 19 years ago, attending home births. In 2005 she decided to get licensure and opened Bella Natal in Orem, with a second site opening shortly after that in Salt Lake. They currently have 5-6 midwives conducting primarily birth center births. She is very happy to be one of the first midwife groups to participate in this program. Prior to this project it was difficult to get babies screened because of few free resources and difficulty getting mom's to follow up. Now that she has screening equipment, she is close to screening 100% of her births. She knows many other midwives that have machines and who complete/report screening as well.

UTAH EHDI UPDATES

Grants are all current right now; the budget is due tomorrow for CDC. Most people are aware that we have been involved with connecting newborn screening results and immunizations to the statewide cHIE. With the exception of actually connecting to the cHIE, we now have the ability to connect directly through a web interface and the State database –Utah Medical Data (UMD). Beta tests have begun with physician's offices. The only people who are automatically opted in to the cHIE are those covered by the Veteran's Administartion (VA), Medicaid and PEHP users. Dr. Young, at the U of U Pediatrics Clinic is currently part of the pilot project to connect to the CHARM Web interface and he has already integrated the process in to his workflow. He is now referring all children who have not passed or completed their newborn hearing screening directly to Susie Bohning, University of Utah audiologist, to complete the screening that day (those not already completed through the University Hospital Newborn Hearing Program). Susie has agreed to see these babies as they come through the clinic.

There are currently no iEHDI updates. iEHDI is a pilot project of 6 states to send individualized data to the CDC. EHDI data is submitted to the CDC on an annual basis, but at this time it is aggregate. This project is going slowly, and we are not the responsible party for this grant.

The Annual Utah EHDI Conference is scheduled for September 28, 2012. This event is for hospital coordinators and audiologists to come together and discuss issues relating to EHDI. We plan to hold a conference specific to midwives in the near future. Part of our responsibility is to annually convene EHDI partners for a statewide training conference. We have completed site visits to 14 hospitals so far this year. Kurt will present a prepared report from these visits at the next committee meeting. CEO Report cards are still in process. Kurt is also planning a two-day conference to be held in February 2012 that will feature Jay Hall, recipient of the Distinguished Achievement Award of the American Academy of Audiology. This will be for pediatric audiologists and possibly ENTs, with CEU credits available. (This workshop has been moved to May, 2013.)

We have partnered with Davis Early Intervention to help with loss to follow-up. Mark Dewsnup will send Krysta Badger names of enrollees (ages 0-3), she will look up hearing screening results and send back to Mark. If there are no results, or if there are failed results, Mark will continue follow-up with that child. This is a pilot project. Harper asked if Early Intervention (EI) seeks out newborn hearing screening results; those are available through CHARM and some programs will contact Nita if they don't find a match to the child in CHARM. EI tries to get hearing results from the parent or hospital and then they will utilize CHARM. Vanya doesn't know exactly know how much they are using CHARM. Nita only gets calls when the nurses can't find the child in CHARM. She is getting fewer calls so she is hoping they are getting more matches/ information through the CHARM link. Sylvia was under the impression that she couldn't access CHARM without parental consent. That is incorrect, they do not need consent to look at CHARM data. Vanya would like to know if CHARM can run a report to show how many "hits" they have. Rich and Vanya will follow-up on this. Vanya will show Sylvia how to access CHARM herself. There is a possibility of doing a nightly push to CHARM to search the database and pull back data that is not already in BabyWatch BTOTS files. Vanya noted that there was a change made in CHARM that interrupted the connection, they are working to fix that now. BabyWatch will be moving to a web database on October 1st, CHARM should be compatible. Harper asked if it would be useful for someone from Hi-Track and CHARM to come to the next ICC provider meeting, but Vanya said their training is usually with one of their data people. Once BTOTS converts to a web system, Nita will also be able to look up enrollment dates for kids with hearing loss. Vanya does often wonder about the children Nita ask for enrollment on that she cannot find. Lori Ruth is working with Nita to follow-up on some of those children.

We have also been working with the Office of Home Visiting to provide training on newborn screening. This project has been put on hold as few of the programs cannot be trained until they have screening equipment.

Krysta will email Vanya referral site lists. Vanya also mentioned networking the home visiting programs to some of the EI sites to share screening equipment.

Beginning April 1st, all Utah hospitals have moved to weekly HiTrack data submissions. Since 1998 this has been a monthly requirement, but transition to the cHIE has created the need for getting data into the hands of physicians sooner. During beta tests for the cHIE, providers found that newborn hearing screening information was often unavailable in CHIE by the two week well-child checks, so State EHDI increased hospital reporting to weekly. Nita noted that there has been little negative feedback from hospitals on this and most indicate that it is actually easier to do data transfers weekly. This was never an administrative rule, just a guideline, so the rule does not need to be changed. HiTrack Web is also available now. Five hospitals have converted to HiTrack Web, uploading directly into the State database. Nita had a conference call with Todd Huffman and Kelly Dick after the switch (Orem Community and Utah Valley Regional) and they have had only a few minor issues which Nita was able to resolve. They are pleased with the transition. Hospitals on HiTrack web are designated on your handout, as well as hospitals that are transitioning. Our goal is that all hospitals will be running HiTrack Web by April 1, 2013. Nita didn't realize how much de-duplication would need to be done because of the weekly reporting, but this should also be resolved when all hospitals have moved to HiTrack web. There have definitely been unanticipated challenges with this transition.

UTAH PHYSICIAN SURVEY

About 7 years ago Dr. White, along with several other colleagues, published results of a national physician survey regarding newborn hearing screening. This group is repeating the survey and have just completed the Utah pilot. Feedback from the Utah pilot will be used to refine the survey prior to national distribution.

For the Utah pilot, there were 177 responses to the survey (20% response rate). This was similar to the first survey, and it was distributed in essentially the same way. See Dr. White's presentation for results showing the 2005 survey data to the 2012 data. The common theme found through this pilot is that we are as effective educating physicians about newborn hearing screening and hearing loss as hoped. Some questions on the survey include: What level of trust do you have in newborn hearing screening? What do you do when a caregiver expresses concern about hearing (this will be edited for the future survey)? What is your best estimate of the earliest age a child can begin wearing hearing aids? Diagnose hearing loss? Some of the responses to these questions are not as positive as the 2005 survey. And some responses could open discussion with the JCIH. Dr. White believes that the verbage of "before 3 months" leads to a belief that evaluation can wait until 3 months of age when it really needs to be done before that. One question asked about specialist referrals a child with hearing loss needs. The AAP recommends that all children with hearing loss receive ophthalmologic and genetic evaluations. 75% of physicians surveyed recommended ENT/Otologic referrals (versus 69% in 2005); this number should be 100%. And referrals to genetics and ophthalmology had a very low response rate of 12% and 2%. There needs to be more education on appropriate/recommended referrals. Sylvia mentioned that a lot of insurance companies will not pay for a visit to the geneticist. As a committee we need to focus on improving access for parents. Another issue may be that many pediatricians think the ENT will take care of the referral. This same question regarding referral to additional specialists was asked to ENTs on the 2005 survey and their response rates were even lower regarding where they would refer a child. More questions included on the survey were: Which conditions put a child at risk for late onset hearing loss? What children (options listed) are candidates for cochlear implants? Does your training prepare you to adequately meet the needs of infants with permanent hearing loss? Dr. White feels that the biggest impact the AAP could have is to argue for changes in medical training focused on children with hearing loss. Dr. Randall asked if there was a question about ongoing training; there was in 2005, but the responses were not very useful. The survey asked the MD's confidence level in explaining the newborn hearing screening process; that hasn't changed much since 2005 with almost half being very confident. The surveys need to be reviewed again to try to determine if those that are very confident

really know the process. In 2005, when the surveys were reviewed it was found that those who answered "very confident" were not more knowledgeable than those that answered "confident". When confidence rates were broken out, 50% were very confident on what to do after a failed hearing screening, but only 4% were confident regarding cochlear implant candidacy. This data suggests that we still have a lot of work to do. Other questions include: Do you screen in your office? (55% said yes, at annual checkups.) Only 74% said they screened if the parent voiced concern, this should be 100%. Only 10% of physicians in Utah said they are using OAE screening. If this number should be higher or lower is subject to debate in the AAP. The AAP EHDI Task Force is saying that since more physicians are doing it, they should be doing it well. 35% of physicians are still just using responses to noise, hand claps, etc. Dr. Harward suggested the questions of "what occurs following the in-office hearing screening" could be re-written to include permanent-conductive loss. This is a 10-minute questionnaire so they do need to keep it short, but Dr. White will consider adding the question. Dr. Randall would also be interested to know why physicians didn't refer to EHDI, whether it was because they don't know they need to, they don't know how to reach them, or they just don't know what EHDI is.

The take home message of these results is that both in state and nationally, with the AAP and AAFP, we have a lot of education to do and not much progress has been made in the last 7 years. Nita mentioned that we do have some physicians who report to us, but a list of physicians providing OAE is not available – we only find out if a mom calls to say OAE was done by the doctor, and we call the office to get information on their testing. Nita mentioned the possibility of a dedicated phone line that physicians could call and leave messages with hearing screening results. This might be easier than filling out a paper. They can also send results by fax, but we have had limited success with the fax back forms. It is something that we should look at again. The data says that we need to continue to be creative about how we affect knowledge, attitude, and practices of physicians. Nationally, this has been about getting the system in place, but not refining the system. That should be the focus with new educational activities. Dr. Harward was surprised that the numbers have not increased with our efforts in the last few years. Dr. Randall would like this to be added to the next "Common Problems" agenda. Dr. White and his team will analyze the pilot data, revise the survey and distribute nationwide by October 1, 2012. He noted that the IRB approval and obtaining the mailing list was much more difficult this year. For the previous survey, they had 2000 responses from 21 states. Any state with more than 50 responses received a separate state report; separate reports could be distributed again this year to show the comparison results. There is some cost to the states in terms of their time and effort, but NCHAM handles all of the out-of-pocket costs. If they get sufficient responses from 20 states, Dr. White will be happy. Dr. Jolma would like Dr. White to send her some bullet points on what physician education should include. She will add this, or a section on the survey results, to the medical home portal. The national data results of this survey may be ready for the 2013 National EHDI meeting.

TELE-AUDIOLOGY PROJECT

Kurt Randall presented on Utah's remote ABR testing, or "RADS" (Remote Auditory Diagnostic Service). This project will explore the possibility of remote diagnostic testing in rural areas to facilitate 1-3-6 goals. Our weakest area in meeting the 1-3-6 EHDI goals is the 3 month goal of diagnosis. For this project, we have partnered with Michele Thompson, midwife in Mt. Pleasant, who has been a part of the Homebirth Hearing Project since March of 2008. Vivosonic ABR equipment has been placed with Michele, who co-ordinates the testing in her home. Dr. Stephanie McVicar connects to Michele's equipment using Bomgar technology where she can "take over" and conduct the ABR from her office in Salt Lake. We have completed diagnostic ABR's on five children, to-date, through this process. Michele hopes the next few tests can be on infants. She has been in touch with Charisse Russell at Sanpete Valley Hospital and will partner with Charisse if there are babies from that program who need ABR. The previous ABRs have completed in Michele's home as homebirth parents are more comfortable there, but follow-up for Sanpete babies will be done at the hospital. The children that have been tested so far are children that have not passed newborn hearing screening, including one who had

meningitis and needed follow-up. For these ABRs, click and tone burst tests were completed, but bone conduction testing has not bee attempted yet. Five more evaluations will be completed for infants/children for this project. We have not done any marketing on this project as this is still proof of concept to make sure the process works. We have identified one toddler with an irregular ABR and referred him for behavioral testing.

There has been talk about tele-audiology nationally for years and many people say they are doing it, but very few really are. With this project, we are actually taking the piece of equipment to the community and using Skype to video conference and control the piece of equipment during diagnostic testing. Once we are beyond the pilot phase, we will have to work on getting financial (insurance/Medicaid) coverage, as tele-audiology may not be covered. Michele mentioned that Charisse's largest problem at the hospital is that once people leave the hospital she has a hard time getting them back. If she had the ABR capability prior to discharge it could prove helpful. For this pilot, the Vivosonic equipment ($20,000) is housed with Michele. (The Thunder Bay group mentioned in this discussion, ships the equipment to locations as necessary.) The most challenging part of this pilot so far has been a working and consistent internet connection as there is only one internet provider available in Sanpete county. The last testing session ran into issues with Bomgar on the Salt Lake side. Daniel Ladner, from NCHAM has been providing technical support and attended the first testing session in Mt. Pleasant. Once five more children have been tested, we will evaluate and decide how to proceed. Sylvia asked if the child must be sleeping to do the testing. This equipment does have a filtering system that allows for some movement, but it would be best if the child could be sleeping (but it can be done without sedation). One of the older children tested just played games (in silent mode) on a cell phone while testing was completed. The intent of this project is not to have augiologist to audiologist interface, but have an audiologist on one end who can perform the test and a lay person on the other end who is trained to place the electrodes. This is meant to expand the reach of audiologist and make it more accessible for families. Dr. White has worked hard to find people who are doing tele-audiology, and has found 6 locations who have tested at least one child.

FAMILY TO FAMILY SUPPORT
Taunya is excused from today's meeting. Lori Ruth informed the committee of the upcoming AG Bell Ice Cream Social on September 5th at 6:00 pm at Smithfield Park in Draper. She will send more information to Nita to distribute. She hopes to expand these socials to Logan and other locations. Kurt will also send this information out through the UCOPA list-serve.

OTHER BUSINESS
Nita would like to discuss with Dr. Park when babies are referred to ENT under 3 months of age and the types of referrals we should be making from an audiology point of view. This will be added to the agenda for the next meeting. Mandated annual public meeting training with Lyle Odendahl is also scheduled for the next committee meeting.

USDB has hired a new Deaf PIP Director, Paula Pittman. She will be starting with USDB on September 4th. We hope she will assume the Deaf PIP consultant position on this committee. Lori Ruth has been attending this meeting from USDB and we would like her to continue to attend. Dr. White motioned to make Lori a voting member, Harper seconded the motion. Nita will add this to the agenda as a voting item for the next meeting. Lori represents a number of constituents/associations and Paula represents PIP/key communication systems.

Dr. Jolma would like to add hearing loss to the (pediatrician) quality improvement projects required for Part IV. (More information available at a later time.)

Dr. White also mentioned that some state's EHDI teams give educational presentations to pediatrician offices. Idaho has been doing this with great success. Lori does call the audiologist when she gets a referral from Nita to

ask the audiologist why the referral did not come from them before the State's referral. Vanya noted that EI has been contacting some doctor offices and doing some lunches. Dr. Harward would like EI staff to include newborn hearing screening with those meetings, if possible. We will meet with Vanya and provide more information on what could be included and how much time they schedule. A one page handout would probably be the best. Vanya will research what is now being provided.

Next meeting will be held November 13, 2012.
Adjourned by Dr. Harward at 11:05, vote to adjourn Karl White, Sylvia White.

Advisory meeting schedule for 2012: *November 13, 2012*. 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.

Mark your calendars for the 2013 meetings: 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.

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