

**EHDI Advisory Committee  
Meeting Minutes  
May 3, 2010  
1:00-4:00 PM  
Indiana State Department of Health**

In Attendance:

Bob Bowman  
Gayla Hutsell Guignard  
Christopher Miyamoto  
Cindy Lawrence  
Teri Ouellette  
Naomi Horton  
Allan Diefendorf  
Greg Cochran  
Glenda Zmijewski  
Kelly Dibenedetto  
Judith Ganser  
Fernando Escobar

Interpreters: 2 were present for today's meeting

The meeting began at 1:03 with Bob Bowman welcoming everyone and each person giving a brief introduction. Bob welcomed the guests and reminded all of the Hands & Voices Communication Ground rules.

Gayla asked that if committee members had updates for the group that they email them to Gayla prior to the next meeting. It will save a great deal of time and we can shorten our meetings if this is successful.

Review of the previous minutes was completed. Cindy Lawrence requested one change be made to clarify the coverage of SKI\*HI across the state and Naomi Horton recommended the correction of a spelling error in one name. The minutes will be changed. Allan Diefendorf motioned that the minutes be approved with a second by Fernando Escobar. The minutes were approved.

Program Updates:

Allan discussed that there are plans for NICU babies to provide more family support with audiology being called in to talk to families if the baby doesn't pass 2 screens. For long stay babies, Riley is developing a plan for in-patient ABR diagnostic testing.

Fernando Escobar discussed how much the genetics of hearing loss is changing. More genes are being identified and we need to find out where and how we can help these

families. It is not simply about detection, but how we need to manage the children identified with hearing loss.

Judy Ganser reported on the needs assessment that they are working on for all programs for the federal government. It is a 5 year plan. In the health care reform act, money has been allocated for home visiting programs (prenatal through age 5). Programs like Healthy Families and Head Start may be programs that would apply. Right now, they are not sure how much money is available. Gayla asked when the funding would be awarded. Dr Ganser was unsure because the details are still undefined, but the application for this grant must have a 5 year plan and show results in the first 3 years.

Teri Ouelette reported that they will be an official site for a program called Professional Preparation for Cochlear Implants. Professionals from the Midwest who are interested in working with children with CI's will attend.

Naomi Horton, HEAR Indiana Executive Director reported on a successful Talk, Walk Run event on May 1. She reminded everyone of the education scholarships available for students who support an auditory oral, auditory verbal approach and agrees to stay in Indiana and work. Information is available on the website [HearIndiana.org](http://HearIndiana.org). The Youth Leadership camp will be held July 18-23.

Kelly Dibenedetto announced that Hands & Voices has 6 new board members. They recently sent out the new e-newsletter. The family conference was held on March 13 with over 200 attendees. On August 7 there will be a family picnic and the first fund raiser will be held on Dec 4 with a Breakfast with Santa at the Columbia Club. Kelly reported that H&V's has had 20-30 advocacy calls from parents recently about many issues; one being schools lack of providing FM systems for student. The Guide by Your Side program has 40 families receiving services. A new guide for children with unilateral hearing loss has also been hired. All GBYS parent guides attended a full day of training on March 12.

Cindy Lawrence, Outreach Services: Cindy asked if everyone had received the email newsletter. Many had not. Gayla will send Cindy the email addresses of the committee members and Cindy will make sure it is sent out. It has information on many various summer camps. On May 20, 2010 there will be a one-day conference for families regarding transition from First Steps to Part B. On May 22, 2010, there will be a quarterly training for the SKI\*HI Parent Advisors. The GBYS parents have been invited to attend. Dr. Chris Miyamoto will be one of the speakers and another speaker will be from the Clerc Center at Gallaudet University. Cindy may try to get a meeting for May 21 for local audiologists to attend. The FLIP program (Families Learning in Play) will host a summer picnic. Clifford the Big Red Dog will be there in July and Biscuit the dog will come in August. Cindy passed out fliers regarding free baby sign classes to families who have children with hearing loss. Naomi Horton asked about Camp Willard and if it was opened to kids who don't use sign language. The cost is about \$300 and there will be interpreters for all. Teri Ouellette asked Cindy if she could attend the transition meeting as there may be families who would like to transition to St Joseph's Institute for the Deaf.

Glenda Zmijewski announced that Outreach is partnering with Barnes & Noble to do a book fair May 14<sup>th</sup> at Clearwater Crossing. Glenda also discussed the Deaf Mentor program through Outreach. The program currently has 6 people and staff is looking for more. Glenda described the program where a deaf mentor will work with the parents in the home to assist with communication access, give practical suggestions, identify other cultural needs, teaching families how to read to their children and looking at the home environment to make sure that there is open communication. Glenda said that many referrals come from SKI\*HI, but some through “word of mouth” and through IFSPs or IEPs. Families with children birth to 8 years of age are eligible. Glenda stated that they were very open to having mentors for children who are auditory-oral. Glenda also stated that they would like to develop tools to assist families in determining if their child is making adequate progress. When asked about compensation, Glenda said currently, all of the Deaf Mentors are ISD employees and earn a stipend for their weekend or evening deaf mentoring services. When asked if others could be compensated, Cindy responded that the stipend is currently only available to ISD employees.

Greg Cochran, representative from the Indiana Department of Education attended the meeting today in place of Dawn McGrath, Director of Special Ed. Greg stated that they were quite busy with various programs and monitoring processes.

Chris Miyamoto reported that his pediatric ENT practice continues to grow about 30% each year.

Gayla Hutsell, ISDH State EHDI Coordinator: Gayla had many topics to discuss.

- Seven people from ISDH and a few from Outreach presented at the National EHDI Conference
- Two state meetings were held and the state plan was developed with the input of all Indiana attendees. The plan is included in the handouts.
- Two progress reports for the CDC and HRSA grants have been completed
- Gayla announced the Equipment Grant had been funded and the process has gone through the legal office and the applications for this equipment will soon be disseminated. It will be emailed to the hospitals for screening equipment (6 AABR units) and to audiologists (3 Diagnostic ABR units). This is a 3 year grant so we hope to have money for additional equipment for the next 2 years. It is hoped that this will help build capacity for diagnostic centers and improve screening referral rates.
- The 6<sup>th</sup> Annual Family Conference was terrific and feedback reflected that the attendees thought it was balanced, and they liked the exhibits and presentations.

Molly Pope gave a brief update on the EHDI Regional Consultant activities.

Julie Schulte, EHDI Follow-up Coordinator, spoke to the committee about the National Initiative for Children’s Health Care Quality (NICHQ) project, in which the overarching goal of the project is to improve access to care for children with hearing loss. St Vincent

Hospital has partnered on this project as a trial site. During the review, it was discovered that it is taking a longer for families to get in for the initial follow-up diagnostic when using First Steps (FS). It was found that families who used their own insurance could get in for follow-up much faster. Staff at St V. is offering families a choice during this trial of using FS or private insurance. Julie briefly addressed some other areas that NICHQ project is looking at including ABR follow-up in the NICU and expanding the direct referral to audiology option to other hospital facilities.

Kelly Dibenedetto showed the new Hands & Voices DVD titled "Loss & Found". All hospitals will receive a copy of this, however distribution of the DVD and accompanying education needs to be planned. It is hoped that maybe it could be used in prenatal classes or on the mom web channel that most hospitals now have. Gayla asked for suggestions from the group. Fernando suggested contacting the Prenatal Nurses Society. Dr Ganser suggested obstetricians. Naomi wondered if it could be linked to the website for social networking is a good way to get information out to the public. Lisa will check with National H & V to see if that can be done. Another suggestion is to give a copy to families whose baby does not pass the screening. It could be attached to the Hearing Certificate. All newborn screeners should also view this video. Naomi also suggested that if more copies are needed, perhaps a small group of Wabash College students who are interested in social projects related to hearing could assist in the duplication process.

Gayla gave a brief presentation on the components of EHDI that are listed at [infanthearing.org](http://infanthearing.org). She gave examples of work that EHDI is doing or could be doing within some of the components:

Medical Home-1) An EHDI Facts sheet was sent to Indiana pediatricians with the IBDPR mailing, 2) The EHDI Toolkit for physicians which was developed by this group is now in EARS and will be implemented.

Newborn Hearing Screening-The Regional Consultant visits to Indiana hospitals exceeded our goal of 80% (94%) this year. In the coming year, among other things, the RCs will be working to help hospitals in need of improvement for due to exceptionally low or high screening referral rates.

Diagnostic Follow-up-Gayla also reported that Indiana's LTF/D was 15 % for 2008 and that Indiana is in the top quarter of states and territories. Dr. Ganser asked if we share this information with the hospitals. She felt like we needed to get the word out about our successes. Teri suggested that we report our data to Sound Medicine. We will also soon begin to use the EHDI-Grams for hospitals and audiologists. It was also suggested to review where the diagnosed infants live and what services are in their area.

Gayla also wanted input from this group about long term follow-up data points. Already included on the EHDI Long-term Follow-up (ELF) form is DOB, Date of diagnosis, date of amplification, date of IFSP, # of GBYS visits, services received (PT, OT, DT, SLP), access to providers, primary language spoken in the home, communication method. Some suggestions included an outcome measure for language development. There was some brief discussion regarding the need for better long term assessment of children who are deaf or hard of hearing. It was suggested that we could help FS develop a specialized system for these babies. Another suggestion was what additional referrals have been

made and the date of those referrals, continued tracking of communication method as it may change over time, asking parents if the services they are getting are what they thought they would be getting. Everyone should contact Gayla with ideas for long term follow-up data points.

- Gayla reminded everyone that the next meeting is Aug 2, 2010. We will again form subcommittees and look at the following areas; Audiology Services, NICHQ spread, Early Intervention and Risk factors.

Bob announced the meeting was over and it was officially adjourned at 4 PM. Future meetings will last two hours as agreed by this committee.