

**EHDI Advisory Committee Meeting**  
**Indiana State Department of Health**  
**2 N. Meridian St., Indianapolis, IN 46204**

**August 2, 2010**

Bob Bowman called the meeting to order. Due to space constraints, subcommittee work (Medical-Risk Factors, Early Intervention) was done at the beginning of the meeting from 1-2pm.

A motion was made to approve minutes from the last meeting by Dr. Fernando Escobar and seconded by Dr. Allan Diefendorf. All were in favor of approving the minutes as written and distributed.

Dr. Ganser asked if there is a new representative from the Dept. of Ed – Gayla will check into this.

Everyone was asked to review the Communication Ground Rules.

**Risk Factor Subcommittee Report** – Diefendorf, Escobar, Bowman, Schulte, Ganser

The group agreed that ISDH has a role but should not shoulder all of the work/follow-up for babies with risk factors. The EHDI program currently follows children with the following risk factors: 1) family history of permanent childhood hearing loss, 2) hyperbilirubinemia, 3) craniofacial anomalies that affect development of the ear, and 4) in utero infection. Currently EHDI sends a letter to mom after a child is identified as at risk and then letters are sent at about 7 months of age to mother and the child's primary care provider regarding the need for a follow-up diagnostic evaluation between 9 and 12 months of age (sooner if the parent has concern that hearing loss exists).

It was agreed that EHDI needs to continue to work with pediatricians and family practitioners to provide education about hearing loss, Universal Newborn Hearing Screening (UNHS) follow-up babies who do not pass and follow-up for children with risk indicators. It was also suggested that perhaps development of a CBT (Computer Based Training) for physicians and discuss with hospitals the possibility of making it mandatory. Lastly, subcommittee members agreed that genetic disorders/syndromes should be added to the risk factors followed by EHDI.

EHDI staff will look at the children diagnosed with hearing loss over the last 5 years and see what proportion have a risk factor and what that risk factor is. Staff will also look at data items that ISDH has access to and see if others would be appropriate to follow (i.e. low apgar scores and low birthweight). There will be some difficulty in obtaining this information from the old database, however once available, this data will be shared with the EHDI Advisory Committee.

**Early Intervention Subcommittee Report**-Downer, Ouellette, Lawrence, Crace, Horton, DiBenedetto, Hutsell Guignard

Dawn Downer led the discussion and reported that there are a number of changes being discussed regarding First Steps through FSSA. One possible change related to hearing is that follow-up

audiology testing may no longer be covered on babies who did not pass UNHS or babies who pass but later need to be evaluated due to having a risk factor for late onset hearing loss. All changes are still being discussed among FSSA and no final decisions have been made yet regarding coverage of follow-up testing. Dawn suggested that if this change occurs, then families could be referred for follow-up testing through their Medical Home who could also assist in scheduling and facilitating follow-up. Once a child is diagnosed they can be referred to FS for EI services. Gayla indicated that 60% of states already follow this model in which babies are not referred to Part C until after diagnosis. Dawn also provided brief information about the funding deficit First Steps is experiencing and stated a need for First Steps to be viewed as one option among several options (i.e. Early Head Start) for receiving early intervention services. Gayla informed the committee about the upcoming American Speech-Language Hearing Association (ASHA) EHDI Virtual Conference slated for late October. Gayla and Maureen Greer (a former Part C Coordinator for Indiana and Executive Director of the Infant-Toddler Coordinators' Association) have prepared a presentation for the conference entitled, "EHDI Screening to Part C Planning: Putting the Pieces Together; How the Systems are Designed to Work."

### **EHDI Long-term Follow-up (ELF) form**

At the last meeting, advisory committee members were asked to think about what data EHDI should gather in terms of long-term follow-up. A handout of the current EHDI Long-term Follow-up (ELF) form, which is used by the Guide By Your Side (GBYS) Parent Program Coordinator and the EHDI Parent Consultants. GBYS Parent Guides will also begin to have access to this form through the EHDI Alert-Response System (EARS). The following input was shared by members: 1) Questions were asked about CI/HA use schedule and therapy; 2) It was asked that the item that says, "SLP direct services" be changed to say something like "direct services"; 3) It was suggested that the form be modified to allow tracking of the beginning date and frequency for each service. It was noted that this information can be difficult to obtain, but that it was suggested that this information could come from each child's Individualized Family Service Plan (IFSP); 4) Consider adding the EHDI re-referral source; 5) Genetic Evaluation and Counseling – if yes, what diagnoses was made? It was also recommended that genetics info be moved up on the page; 6) Need definition of "recommended" as it is confusing as written; 7) Regarding date of CI – which date is this activation or surgery – activation date is what is needed here; 8) What is a religious waiver? A family has the right to refuse screening and follow-up based on religious objection. The form has to be signed and returned to ISDH/EHDI; 9) Communication methodologies section – can it be modified so more than one can be selected? May want to consider combining AO and AV and changing those to current terminology which is "Listening and Spoken Language"; 10) Are you able to track changes in history over time? Need to be able to track changes over time; 11) May want to consider including some kind of data points –i.e. language quotients; 12) May want to add a student test number from the DOE to enable matching at a later time; 13) Perhaps consider a question regarding whether the child has been referred to a developmental pediatrician; 14) Would it be possible to get AEPS scores to add to the children's files?

At the conclusion of the discussion, it was recommended that anyone on the committee who has additional suggestions should send those in to Gayla within the next week.

Bob Bowman adjourned the meeting at 3:10

Meeting Attendees:

Bob Bowman

Gayla Hutsell Guignard

Judy Ganser

Julie Schulte (acted as scribe)

Cindy Lawrence

Jodee Crace

Dawn Downer

Fernando Escobar

Allan Diefendorf

Chris Miyamoto

Naomi Horton

Kelly DiBenedetto