

EHDI Advisory Committee Meeting  
Indiana State Department of Health  
November 1, 2010

In Attendance:

Gayla Hutsell Guignard	Kelly DiBenedetto
Christopher Miyamoto	Judith Ganser
Cindy Lawrence	Jodee Crace
Teri Ouellette	John Hill
Allan Diefendorf	Lisa Kovacs
Julie Schulte	

Minutes: Molly Pope

Interpreters: 1 was present for today's meeting

The meeting began at 1:05 with Gayla Hutsell Guignard, EHDI Program Director, welcoming everyone and each person giving a brief introduction. Gayla welcomed the guests and reminded all of the Hands & Voices Communication Ground rules.

Minutes of the last meeting were reviewed. Teri Ouellette was listed as present although she did not attend. The minutes will be revised to reflect that change. Kelly DiBenedetto moved to accept the minutes and Allan Diefendorf seconded. The minutes were approved.

Gayla welcomed our newest committee member, John Hill from the Department of Education. John has been with the DOE for 10 years and serves on the boards of the Indiana School for the Deaf and the Indiana School for the Blind as the Dept of Ed representative. He also assists schools with Medicaid reimbursement issues. Other members introduced themselves to John.

Gayla reviewed recent activities with the Board members which included;

- Asha's Virtual EHDI Conference- in which Gayla and Maureen Greer presented on EDHI Screening to Part C Service Planning
- 4 presentations from ISDH submitted for the 2011 National EHDI Conference
  - Risk Factors
  - Managing Systems' Change
  - EHDI and GBYS
  - Region 4 Genetics Collaborative EHDI Action Guide

Gayla then discussed EHDI's response to First Step changes. There were many conference calls with hospitals, audiologists, physicians and SPOEs held in September in efforts to make sure that all stakeholders understood that changes would be implemented in the EHDI process effective October 1. EHDI developed recommended hospital procedures that ask hospitals to schedule the outpatient diagnostic evaluation prior to discharge for babies who did not pass 2 screens. Babies with risk factors should be referred to the PCP for follow-up testing at 9-12 months of age. The original 4 risk factors will still be reported to EHDI through EARS. Gayla described the request for each hospital to submit their plan to ISDH by Sept 22, 2010. To date, 65 birthing facilities have turned in their procedure. Of this

number, 52 are referring directly to audiology. Others have various plans in place. ISDH also requested audiology facilities to report which types of insurance they accept. All Level 1 Centers responded to this request. Hospitals were provided with a sample referral form that could be modified for their use. At their request, audiologists have been provided with a sample waiver form that they can use to have families sign related to being informed about First Steps and their wish to be referred or not. Because babies diagnosed with hearing loss will now enter First Steps and other public and private intervention services at the point of diagnosis, audiologists have been informed that they need to make sure make sure that appropriate referrals to early intervention occur within 2 days of diagnosis (per Part C federal law)

Julie Schulte, EHDI Follow-up Coordinator, reported on the analysis of some risk factor data. The report was based on 275 babies born between August 25, 2007 & June 15, 2010. All data came from the EARS system. 46% had risk factors and 54% did not. Please review the handout for specific information.

Lisa Kovacs, Guide By Your Side (GBYS) Program Coordinator discussed GBYS data gathered regarding the first 13 months of the program (September 2009 through September 2010). During this period of time, 139 families were contacted by Lisa. Of this number, 82 families enrolled in GBYS. Please review the handout for detailed information. Lisa stated that one goal of Hands & Voices is to extend their services to families of older children. Currently there is no funding for this effort. John Hill reported that InSource receives funds to conduct parent support activities related to transition and Individualized Education Plans. Lisa thanked John for this information and indicated that the long-term vision is that GBYS will be available to families with children birth through 21 across the state of Indiana.

Cindy Lawrence, Director of Outreach Services for Deaf and Hard of Hearing Children reported on the National Early Childhood Assessment Project (NECAP). Outreach has signed a letter of intent to work with the University of Colorado on this Centers for Disease Control (CDC)-funded project. Goals of the project include support for states in implementing a standard assessment battery for children from birth to 4 years of age, creation of a national data base, to assist states in interpreting assessment results and using these to drive intervention goals and decisions. In addition, the study will characterize the service delivery models of EI in the U.S. and determine EI program characteristics related to successful language outcomes for children who are d/hh. Please review the handout for more detailed information.

Some questions were raised about the NECAP program. Issues regarding privacy were raised as this is not a blind study. Who will have the data? What will it be used for? Will it be shared with any other entity? Who can access the data later? One advantage pointed out that this study is supported by the CDC and must have gone through an institutional review board. Ongoing discussion could not continue due to time constraints.

Kelly DeBenedetto moved that the meeting be adjourned. Teri Ouellette seconded the motion. The meeting was adjourned at 3:05 PM.