2000 EHDI State Planning Meeting

Agenda

DAY 1 - WEDNESDAY, NOVEMBER 8

8:30 - 9:00 Welcome, Introductions, and Overview

9:00 - 10:00 Session I: Collaboration - Activities and Roles

Moderator: June Holstrum

Panel:

DSHPSHWA - Pat Dewey
EHDI Technical Assistance Center - Karl White
HRSA - Irene Forsman

JCIH - Terese Finitzo NIDCD - Amy Donahue OSERS - Lisa Holden-Pitt

10:00 - 10:15 Break

10:15 - 12:00 Session II: Infrastructure and System Building

Activity I-A. Establish and implement a State or regional surveillance and data tracking system to assure minimal loss to follow-up by monitoring the status and progress of infants through the three components of the EHDI program (screening, identification, and intervention).

Activity I-D. Develop mechanisms to identify and collect standardized data on infants/children with late onset or progressive hearing loss.

Activity I-G. Collaborate with State programs such as Maternal and Child Health, Part C of the Individuals with Disabilities Education Act, private service programs, and advocacy groups to build a coordinated EHDI infrastructure.

10:15 - 10:30 The CDC Perspective Coleen Boyle

10:30 - 10:40 - Interaction with States

Vince Campbell

10:40 - 12:00 Barriers and Enhancers: 10:40 - 10:50 Introduction: Karl White

10:50 - 11:35 State Examples:

Maine: Ellie Mulcahy

Arkansas: Laura Smith-Olinde Hawaii: Beppie Shapiro

11:35 - 12:00 Discussion

12:00 - 1:30 Lunch and Demonstrations [Hi-Track, OZ, Neometrics]

1:30 -2:45 - Session III: Collecting Standardized Data for Evaluating EHDI Programs

Activity I-C. Collect standardized EHDI data (including the type of hearing loss and type of

intervention services) from appropriate sources, such as birthing hospitals, diagnostic centers and/or intervention programs.

1:30 - 1:45 Introduction - June Holstrum

1:45 - 2:15 State Examples: Minnesota - Penny Hatcher

Utah - John Eichwald

2:15 - 2:45 Discussion

2:45 - 3:00 Break

3:00 - 5:00 - Session IV: Populating the Database?

Activity I-B. Develop standardized data collection and tracking methods (i.e., linking with birth certificate files) and forms, and data analysis plan in collaboration with CDC and other recipients.

3:15 - 4:15 Strategies to Populate the Database

Introduction: Brandt Culpepper

Vital Statistics, EBC - Mary Anne Freedman

Hi-Track - Karl White

OZ - Ken Pool

Neometrics - Diana Laukaitis

4:15 - 4:30 State Examples:

Iowa - Lenore Holte

Massachusetts - Janet Farrell and Saul Franklin

4:30 - 5:00 Discussion

DAY 2 - THURSDAY, NOVEMBER 9, 2000

8:30 - 10:15 Session V: Data Integration

Activity I-H: Integrate with other screening programs that identify children with special health care needs such as newborn blood spot screening and birth defects surveillance.

8:30 - 9:45 Strategies for Data Integration

Introduction: Ken Pool

Blood Spot screening - Brad Therrell Birth defects registries - Cara Mai Immunization registries - Rob Linkins Part C - Child Find - Lisa Holden-Pitt

All Kids Count - David Ross

9:45 - 10:15 Discussion

10:15 - 10:30 Break

10:30 - 12:00 Session VI - Portability, Integration, and Confidentiality

10:30 - 11:30 Introduction: Vince Campbell

HIPPA, HISSB - Helen Regnery

IRB/OMB - Mark Long

11:30 - 12:00 Discussion

12:00 - 1:30 Lunch and Demonstrations

1:30 - 2:45 Session VII: Data Integration - State Examples 1:30 - 2:15 State Examples Introduction: Irene Forsman Colorado - Vickie Thomson New Jersey - Pam Costa Michigan - Elise Dimon

2:15 - 2:45 Discussion

2:45 - 3:00 - Break

3:00 - 4:00 Session VIII: Next Steps Introduction: June Holstrum List Serves & Web Board - Roy Ing Committees Reports:

Data items and Definitions Committee - Sherry Spence
Data Sources Committee - Vickie Thomson
Populating the data base and Data Integration Committee - Pam Costa
Reporting System Committee - Elise Dimon
Program Evaluation Committee - Lenore Holte
Family Issues and Concerns Committee - Beppie Shapiro