



# **EARLY HEARING DETECTION AND INTERVENTION PROGRAM GUIDANCE MANUAL**

**February 2003**



**DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
Centers for Disease Control and Prevention

# **Early Hearing Detection and Intervention (EHDI):**

## **Guidance for State Health Department EHDI Programs**



**February 2003**

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Centers for Disease Control and Prevention**

Julie Louise Gerberding, M.D., M.P.H., *Director*

**National Center on Birth Defects and Developmental Disabilities**

José F. Cordero, M.D., M.P.H., *Director*

**Division of Human Development and Disability**

Edward Brann, M.D., M.P.H., *Director*

**Early Hearing Detection and Intervention Program**

---

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### **CDC**

Myron (Mike) Adams, M.D.  
Krista Biernath, M.D.  
Coleen Boyle, Ph.D., M.S., B.A.  
Edward Brann, M.D., M.P.H.  
Larry Burt, M.P.A.  
José F. Cordero, M.D., M.P.H.  
Pamela Costa, M.A., B.A.  
Brandt Culpepper, Ph.D., CCC-A, FAAA, B.S.  
Taren Dailey, B.A.  
Beverly Dozier, J.D.  
Chrystal Ford  
Marcus Gaffney, B.S.  
Melanie Gamble, M.P.H.  
Rhonda Gilley

Scott Grosse, Ph.D., A.B.  
June Holstrum, Ph.D.  
Roy Ing, M.D., M.P.H.  
Maggie Kelly, B.A.  
Aileen Kenneson, Ph.D., M.S.  
Rene Lavinghouze, M.A.  
Katherine Lyon-Daniel, Ph.D.  
JoAnna Powell  
Lee Ann Ramsey, B.B.A., G.C.P.H.  
Marcia Victor, M.P.H., B.S.  
Susanna Visser, M.S. B.A.  
Belinda Ware  
Connie Whitehead, B.A.

### **Consultants**

*Irene Forsman*, M.S., R.N., Nurse Consultant  
Integrated Services Branch  
Division of Services for Children with Special Health Needs  
Health Resources and Services Administration  
Maternal and Child Health Bureau  
*Bradford (Brad) Therrell*, Ph.D., Director  
National Newborn Screening & Genetics Resource Center  
*Karl White*, Ph.D., Director,  
National Center for Hearing Assessment and Management

### **State Review Panel**

Ken Smith—Alaska  
Denise Ramsey—Iowa  
Marshall Tyson—North Carolina  
Leslie Beres-Sochka—New Jersey  
Janet Evans, Ann Filloon—Florida  
Nancy Pajak—Wyoming  
Carol Hassler—Vermont  
Michelle King—Kentucky  
Will Oden, Bruce Ellard,  
Jacque Cundall—Tennessee

David Laszlo, Astrid Newell--Oregon  
John Eichwald—Utah  
Melinda Sanders—Missouri  
Mille Sanford—Arkansas  
Ellie Mulcahy—Maine  
Vickie Thomson—Colorado  
Penny Hatcher—Minnesota  
Janet Farrell—Massachusetts  
Ruth Fox—New Hampshire

### **Editor**

Denise Webster & Associate

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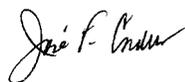
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## FOREWORD

The Centers for Disease Control and Prevention (CDC) is pleased to provide you with the Early Hearing Detection and Intervention (EHDI) Program Guidance Manual. The purpose of this manual is to assist states and other stakeholders in developing or enhancing comprehensive EHDI programs. In support of Healthy People 2010, EHDI is a growing national public health initiative aimed at enhancing the lives of children with hearing loss and their families.

Healthy People 2010 is the prevention agenda for the Nation. It is a statement of national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats. The Healthy People 2010 goals specific to EHDI include: a) all infants are to be screened for hearing loss by one month of age, preferably before they are discharged from the hospital; b) infants who screen positive for hearing loss will be referred for an audiological evaluation by three months of age; and c) infants with confirmed hearing loss will be referred for comprehensive medical and intervention services by six months of age.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) is pleased to provide support in collaboration with other federal agencies, organizations, our partners, and the public in the accomplishment of these national public health initiatives. All of those who have contributed to the preparation of this manual hope that you find it to be a useful tool. We look forward to working with you on achieving a common goal—helping children to develop and reach their full potential.



José F. Cordero, M.D., M.P.H.

Assistant Surgeon General

Director

National Center on Birth Defects and Developmental Disabilities





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## PREFACE

Hearing loss occurs in approximately 12,000 children each year (3 of every 1,000 births) and, when undetected, can result in developmental delays. Early Hearing Detection and Intervention (EHDI) is a national initiative that supports the early identification of infants with hearing loss through screening, audiologic and medical evaluation, and enrollment in early intervention and family to family support services when needed. Without EHDI programs the average age of identification of children with hearing loss is 1 1/2-3 years of age, which research suggests is already beyond the start of the critical period for optimal speech and language acquisition. Many children with hearing loss are now identified and receive intervention by 3 months of age. When a child's hearing loss is identified soon after birth, families and professionals can help make sure the child receives timely follow-up testing and intervention services at an early age. These services help ensure that children acquire communication and language skills that will last a lifetime

For more than a decade, advances in hearing screening technology coupled with a strong commitment from a wide range of health professionals and the public, have provided the environment to establish comprehensive EHDI programs. More than 35 states have passed legislation addressing hearing screening, diagnosis, and/or intervention. Federal agencies, including the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the National Institutes of Health, and the Department of Education have provided national leadership and financial support for states and organizations to build the infrastructures necessary for EHDI programs. As a result of these collaborative efforts, the national agenda to promote early identification and intervention continues to move in a positive direction.

As states and organizations prepare to establish, improve, or evaluate existing EHDI programs, they are faced with numerous challenges. Although hearing screening technology exists, and nearly 70% of all U.S. newborns are screened for hearing loss, we cannot solely rely on technology. Technological advances must be accompanied by improvements in public health systems to assure that the potential gains for the nation's children are realized. Comprehensive programs and systems must be in place to ensure infants transition smoothly through other key EHDI components, including rescreening, audiologic and medical evaluation, intervention, and family to family support services. Without appropriate follow-up and interventions, the true value of screening newborns for hearing loss cannot be achieved.

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Many stakeholders realize the complex and ever-changing relationships between the components of the EHDI process. While some states have had great success in screening nearly all newborns, there are many challenges and barriers to having similar success in tracking, referral, and follow-up through the diagnosis and intervention stages. Knowing which children have completed the EHDI process is essential to successful follow-up. This can be accomplished through the development of comprehensive EHDI surveillance and tracking systems.

This manual addresses the major steps in establishing EHDI tracking and surveillance systems. In consultation with other federal and state agencies, and several partner organizations, the manual was prepared by CDC's EHDI Program. It has been crafted for use with the realization that one size does not fit all, but in the hope and expectation that it will serve as an unbiased guide to be used in implementing and improving tracking and follow-up of children through the EHDI process. While the manual was written primarily for state and local health and human services officials, it is also expected that it will be used by an array of health care professionals, managed care organizations, and others. All of those who have contributed to the preparation of this manual hope that you will find it to be a valuable tool for accomplishing your respective EHDI program's goals and objectives.

If you have any questions about the information presented in this manual, please contact the EHDI Program at CDC at 404-498-3032 (Phone and TDD). We look forward to your feedback and welcome comments on future editions of this publication.



Edward A. Brann, M.D., M.P.H.  
Director  
Division of Human Development and Disabilities  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

## CHAPTER 1

# Vision, Mission, Goals, Program Objectives and Performance Indicators

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### Vision

The vision of the Center for Disease Control and Prevention's (CDC) Early Hearing Detection and Intervention (EHDI) Program is to promote communication from birth for all children.

### Mission

The mission of CDC EHDI Program is for every state and territory to have a complete EHDI tracking and surveillance system that ensures children with hearing loss achieve communication and social skills commensurate with their cognitive abilities. To do this, it is essential that infants with hearing loss be identified early and appropriate intervention services be initiated. Without early identification and intervention, children with hearing loss may experience delays in the development of language, cognitive, and social skills that may prevent success in academic and occupational achievement.

### Goals

CDC and state representatives developed seven national goals that address the comprehensiveness of the EHDI program, and reflect the ideal achievement. Each national goal has a set of specific program objectives; these objectives are essential in accomplishing each national goal. Each program objective has a quantitative measure (performance indicator) that

can be used to track the progress toward the goals and objectives (see Appendix I for objectives and indicators).

The first three goals reflect the recommendations of other organizations, such as NIH/NIDCD, HRSA/MCHB, JCIH, ASHA, AAA, and AAP (see Appendix II for an explanation of acronyms).

**Goal 1:** *All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.*

**Goal 2:** *All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.*

**Goal 3:** *All infants identified with a hearing loss will begin receiving appropriate early intervention services before 6 months of age.*

These first three goals are frequently referred to as the 1-3-6 plan.

**Goal 4:** *All infants and children with late onset, progressive, or acquired hearing loss will be identified at the earliest possible time.*

A comprehensive EHDI tracking and surveillance system must go beyond the 1-3-6 plan. There is a need for the EHDI system to identify and track infants and young children who are missed or who do not have an identified hearing loss at birth. Primary health care providers (PCPs), parents, and other care providers should refer an infant for screening any time they suspect a hearing loss. Audiologists who later identify infants and children with a hearing loss should report such losses to the EHDI tracking system.

**Goal 5:** *All infants with hearing loss will have a medical home.*

PCPs play a key role in the success of the EHDI program. It is critical that infants and their families have a medical home and that services be coordinated between the medical home and the EHDI program. PCPs can

help families understand the EHDI process and ensure that infants referred for audiologic evaluation complete that evaluation by 3 months of age.

*Goal 6: Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up.*

The EHDI tracking system should include all infants who are identified with a permanent hearing loss, including infants with a mild or unilateral loss. The system should also include infants who have risk factors for late onset or progressive hearing loss and infants and children identified beyond the newborn period with a hearing loss. All identified infants should be referred to intervention services, including medical, educational, audiologic, and family support services. These services must be coordinated among the family, the medical home, early intervention services, audiologists, and other professionals involved in the care of infants and children with hearing loss.

*Goal 7: Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives.*

It is important for each EHDI state program to evaluate how its program is being implemented and the extent to which the objectives are being achieved. Families and other stakeholders should be involved in the evaluation process. Evaluation should be an on-going process. Written reports on the progress and status of the state need to be produced and reviewed regularly.

The EHDI tracking system is designed to minimize the loss to follow-up and ensure that all infants with hearing loss receive timely and appropriate intervention services that will allow them to achieve their optimal level of communication and social skills. This document provides guidance on setting up state-based EHDI programs to fulfill this mission.



## CHAPTER 2

# Planning and Evaluation

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Program planning and evaluation are critical to the successful implementation of EHDI programs. The purpose of planning is to define program goals and objectives and to devise a strategy to achieve them. The purpose of program evaluation is to assess how well the planned strategy is being implemented and whether the objectives are being achieved. Planning and evaluation are interrelated. A thorough evaluation begins with proper planning. Likewise, effective evaluation requires that the data needs for evaluation be considered in the planning process.

This chapter is intended to provide a set of principles that states can use for their own purposes, not a set of guidelines on how states are expected to conduct evaluations. It follows a Framework for Program Evaluation in Public Health published by CDC in 1999.<sup>1</sup> There are six steps outlined in the framework: 1) engaging stakeholders; 2) describing the program; 3) focusing the evaluation design; 4) gathering credible evidence; 5) justifying conclusions; and 6) ensuring use and sharing lessons learned. An adaptation of this framework for community-based groups is also available at the Community Tool Box website.<sup>2</sup>

The availability of resources can be a constraint on the ability to design and conduct thorough evaluations. Hopefully, even the most resource-constrained EHDI programs can benefit by incorporating at least some of these principles into the planning process. Moreover, EHDI programs should consider earmarking a percentage of funds for conducting evaluation activities.

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<sup>1</sup><http://www.cdc.gov/eval/framework.htm#formats>.

<sup>2</sup>[http://ctb.lsi.ukans.edu/tools/EN/sub\\_section\\_main\\_1338.htm](http://ctb.lsi.ukans.edu/tools/EN/sub_section_main_1338.htm)

## Planning

The planning process can be divided into three phases: 1) identifying and engaging stakeholders; 2) describing the program; and 3) developing a detailed work plan.

### *Stakeholders*

Stakeholders are those people who might be affected by, have influence on, or assist the program by contributing resources or ideas. Stakeholders for EHDI programs include, but are not limited to, families and people with hearing loss; everyone involved with one or more aspects of the EHDI process; and public and private decision makers who control rules, statutes, funding, and access to EHDI programs, databases, and services. Because stakeholders can have different values and perspectives, including them in the planning process can help achieve consensus on goals and objectives, clarify everyone's position, and identify possible pitfalls early in the planning process. Soliciting involvement of stakeholders should be a systematic and open process, not one limited to informal networks of friends and associates. It is important to include any groups who could potentially constitute barriers to successful achievement of goals if not involved in setting those goals. Nontraditional stakeholders, such as civic or service organizations, might be willing to assist in the implementation and support of the program. Stakeholders should be consulted in the evaluation of the program as well. A list of potential groups of stakeholders for EHDI programs is included in Appendix V.

### *Describing the Program*

A program description should convey the mission of the program, as well as its goals, strategy, and capacity to accomplish outcomes. A program description should include: 1) a mission statement; 2) goals and objectives; 3) activities to be conducted; 4) resources to accomplish

activities; 5) stage of development and context; and 6) a logic model. However, this may not be the order in which a program description is prepared. It may be helpful to start with a list of intended activities and determine the outcomes expected to result from these activities. This can ensure that the goals and objectives are consistent and achievable. The logic model can then be used to depict the resources, activities, and outcomes. A mission and vision statement could potentially come last. Also, it should be noted that the goals and objectives are likely to vary with the stage of development of the program and the resources available. Initially, goals and objectives might be focused on getting activities up and running.

### Mission Statement

A mission statement may incorporate or build on existing statements from the state department of health or other agencies. EHDI programs working in collaboration with CDC have developed a broad mission statement and seven goals, which are presented in Chapter 1. These statements can be used “as is” or be modified to suit individual state needs. However, each EHDI program should ensure that stakeholders represented on its advisory committee reach consensus on the particular statement of mission and goals.

### Program Goals

A goal is a general, “big picture” statement of an outcome a program intends to accomplish to fulfill its mission. The goal should be written so that the desired outcome is clear. A goal statement should:

- State what a program, or program component, hopes to accomplish during a specified time period.
- Describe the desired outcome the program intends to accomplish.
- Be supported by theory and data review.

- Be appropriate given a program's present situation (context).
- Be reflected in the overall logic model.

### Activities

EHDI program activities include:

- Developing policy (involvement in legislation, rule-making, and funding decisions).
- Providing information regarding screening, diagnostic case management, and early intervention services to the public, parents, providers, and interest groups.
- Developing data systems.
- Coordinating follow-up services.
- Developing and conducting program evaluations.

### Resources

Resources include funds and people. The success of an EHDI program depends on many people beyond the EHDI program itself, including both health department staff and people outside government. A full description of the program should include members of advisory committees, consultants to hospitals, speakers to groups, and the like. It is important to include donated materials and time of volunteers, since the program needs to be aware of the full resources it is using. In addition, funds leveraged from other sources should be recognized, not just funds directly allocated to EHDI programs.

### Stage of Development and Context

A program that has been in existence for several years can achieve more with the same resources than a program that is just getting started. The legal and regulatory context can greatly influence program activities and

outcomes. For example, centralized tracking of screening, follow-up, and referrals requires reporting of individual data by hospitals and other healthcare providers. The ability of a program to achieve goals of documenting high referral rates of those who screen positive and those who are diagnosed with hearing loss depends on the completeness of data reporting. In some states, healthcare providers share this type of information only if legally required to do so; in those states, a requirement to report individual data may be necessary for centralized tracking to take place.

## Logic Model

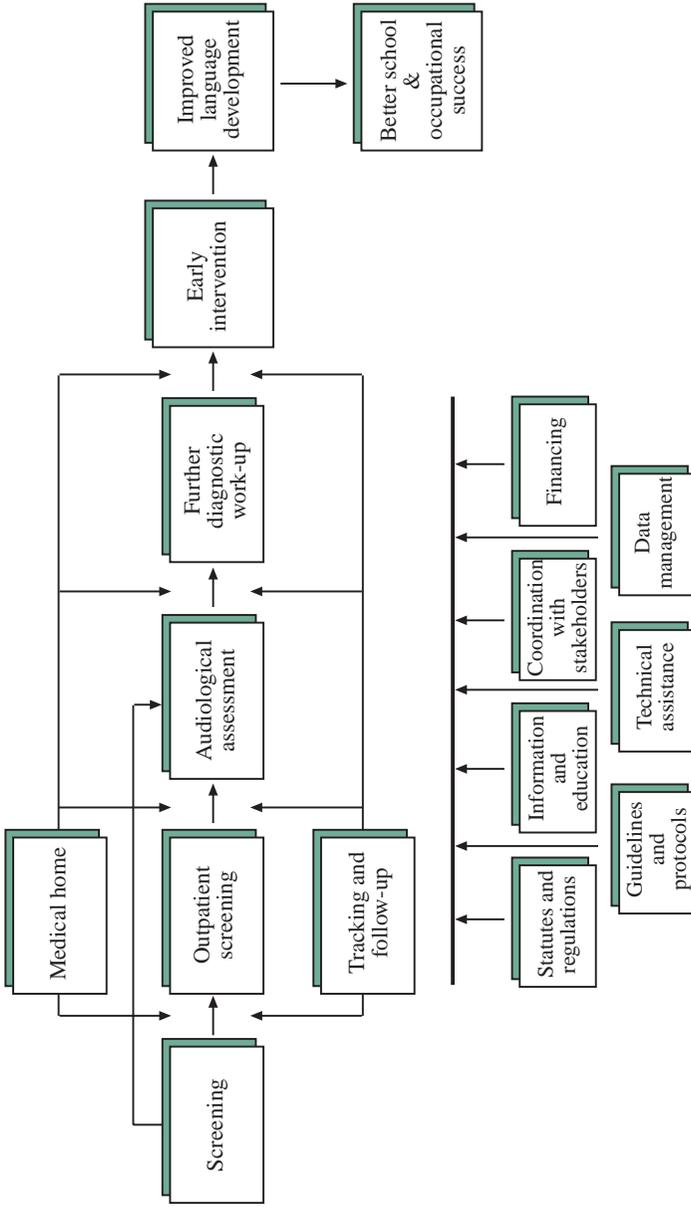
CDC recommends that each public health program construct a logic model as part of the planning process. A logic model is a flow chart that describes how inputs are used to generate outputs and how outputs in turn result in desired outcomes. A logic model can be used to describe either a system or a program. The EHDI system involves multiple stakeholders: parents, hospitals, audiologists, medical homes, early intervention programs, and state health departments, among others, who are together responsible for screening, tracking, follow-up, retesting, diagnostics, and intervention. Successful long-term outcomes of improved language development and full social participation are dependent on the efforts of each of these groups (see Figure 1).

More typically, logic models are prepared from the viewpoint of a specific program. Such a logic model specifies, in general terms, how program inputs, such as staff and money, are translated into program activities (for example, program services, partnerships), which in turn result in immediate program outputs (number of people reached by program activities) and intermediate and ultimate outcomes (awareness, behaviors, health/developmental outcomes). A useful guide to logic models for program evaluation and their use by program managers is available on a University of Wisconsin Cooperative Extension website.<sup>3</sup> Other resources for program planning and evaluation are also available.<sup>4</sup>

<sup>3</sup><http://www.uwex.edu/ces/pdande/>

<sup>4</sup><http://www.cdc.gov/eval/resources.htm>

Figure 1. Logic model of the EHDI system, with program inputs at bottom



In addition to an overall logic model, programs may find it helpful to create more tailored logic models for specific types of activities. For example, one component of a program might focus on family-to-family support by partnering with groups and providing referrals for families with children who test positive for hearing loss. The inputs from the EHDI program would include financial and staff resources. The activities supported by the program could include convening a workshop of stakeholders, training parent volunteers, providing family-to-family support resources, etc. Outputs would include the numbers of parents participating in meetings, numbers of groups formed, etc. Outcomes could include immediate outcomes in terms of parents' familiarity with their child's diagnosis, better knowledge of options, and reduced feelings of stress or anxiety. Longer-term outcomes might include greater utilization of early intervention services and greater satisfaction with services received.

## Developing a Work Plan

A work plan specifies both the measurable objectives and the standards by which they will be measured. The advantages of having a work plan include being able to define intermediate steps, and who is responsible for specific tasks, so that program managers can better monitor whether they are likely to achieve their objectives and assess the performance of their staff and partners.

A work plan should: 1) define a specific, time-framed goal; 2) list objectives for the goal; 3) specify related activities; 4) identify measures of success; 5) delineate a time frame for achieving the goal; and 6) identify team members responsible for the accomplishment of this goal.

A simple template for a work plan might look like this:

Goals for this year		Measures of success		
Objectives	Activities planned to achieve this objective	Sources of data	Time frame for achieving progress	Team members responsible

## Goals

Goals should reflect those of the national program listed in Chapter 1. These may be modified to meet the needs of individual states.

## Objectives

Objectives are criteria by which successful program performance can be assessed. It is important for objectives to be SMART:

**Specific** – identify who, what, and where

**Measurable** – identify how many

**Achievable** – can be attained

**Realistic** – can be attained given time and resources available

**Time framed** – identify when

Objectives serve as the foundation for activities; that is, once an objective is determined, activities have to be identified that will lead to achievement of the objective.

Objectives may include both program outputs and intermediate and ultimate outcomes. In general, more distal outcomes, such as satisfactory language development in school-age children, are difficult to use in program planning and evaluation because of time lags and multiple influences.

Program staff should use the logic model to make sure that objectives are linked to activities that can influence outcomes. For example, EHDI programs seek to minimize loss to follow-up among children identified at hospital discharge as needing further testing. Consequently, an important objective is a reduction in the rate of loss to follow-up. It is important to specify how program activities are expected to reduce loss to follow-up through program outputs and intermediate outcomes.

One EHDI program activity is awareness building among primary care providers (PCPs) of the importance of timely referral for rescreening or diagnosis. Objectives could include measures of program outputs, such as the number of health care providers provided with educational materials or the numbers of provider practices sending representatives to informational workshops. Additional objectives could include intermediate outcomes, such as surveys of the level of awareness of EHDI goals among PCPs or the percentage of PCPs who report urging parents to have children brought in for follow-up testing.

### *Measure of Success*

In order to construct a measure of success, one can ask the question “How will we know when we have achieved a specific goal?” For example, one common goal is to build an effective coalition of stakeholders to support the EHDI program. Program staff must decide what constitutes an effective coalition and be able to define this, perhaps using a combination of measures of coalition size, activities, and perceived influence on outcomes. Measures of success are similar to performance measures or indicators and should be feasible to obtain as well as a quality indicator of your program’s success. For a list of national EHDI performance indicators, please refer to Appendix I.

## Evaluation

An effective evaluation plan can advance a program. Program evaluation should be thought of as a routine, integral aspect of program operations and as a natural extension of the planning process and work plan creation. Perhaps the majority of the work of evaluation has been done in the work plan stage in which the program will have identified its goals, objectives, measures of success, and data collection methods.

Many people are intimidated by the concept of evaluation, which is often confused with research. Research is conducted to add to the general body of knowledge and generally requires control or comparison groups. In contrast, program evaluation is intended to measure the extent to which programs do what they set out to do.

Program evaluation has multiple uses that may differ at various times. The uses of program evaluation include modifying program operations to improve performance, refining program objectives, building stakeholder support, justifying continued program funding, and identifying additional resources needed to achieve objectives. Over the life of a program, the focus of evaluation may differ as well. The focus in early stages may be on developing inputs and infrastructure. Subsequently, the focus may be on correctly implementing activities and identifying bottlenecks. Later in the life of the program, evaluation may focus on measuring the progress in achieving outcomes.

CDC emphasizes the importance of stakeholder involvement throughout the evaluation process. Stakeholders might reject or ignore evaluation findings if they are not appropriately involved in the process. Further, by keeping stakeholders informed throughout the process, misunderstandings can be avoided. Stakeholder involvement early in the process will assist in focusing the evaluation to a state's particular needs.

Ideally, evaluation should be an ongoing process, not just a onetime effort and product. As goals and objectives evolve over the life of a program, so will the need for evaluation and the resources available to fund evaluation activities.

An evaluation work plan specifies the following:

- What questions will be addressed?
- How will information be gathered to address the questions?
- What resources will be needed to conduct the evaluation and where will they come from?
- How will evaluation activities be prioritized given limited resources?

Types of evaluation questions include:

- Have the defined objectives been met?
- Was the program implemented as intended?

- Have stakeholders responded in a way that you expected them to respond? If not, why not?
- What are the barriers to achievement of compliance with testing and satisfaction among families of children who screen positive or who are diagnosed with hearing loss?

Program evaluations typically include a mix of process and goal-oriented or impact (outcome) evaluation designs. Goal-oriented evaluation focuses on the achievement of objectives and takes a quantitative form. Data sources include program data systems and special surveys.

Process evaluation focuses on the delivery of the intended program strategy. It combines quantitative information from administrative data systems and qualitative information from interviews. Qualitative information is essential for understanding factors for success in some areas and barriers to success in others. Qualitative information is gathered through open-ended questions in surveys, personal interviews, community workshops, or structured focus groups. Each group of stakeholders needs to be included in this process. Important issues to consider include understanding of program messages, adequacy of resources (including cultural competency of program staff and service providers), and satisfaction of stakeholders. The goal-oriented evaluation by itself does not account for why objectives were or were not achieved. The combination of goal-oriented and process evaluation is essential for understanding why program objectives have or have not been satisfactorily achieved.

Finally, evaluations should result in written reports (including a plan for dissemination of such reports), which can serve multiple purposes. It is important that evaluation reports identify the important questions that were asked and the answers that were found. Reports should include specific recommendations, including maintaining or changing policies and procedures. A good evaluation report can help guide the planning process and move the program toward success.

## Planning and Evaluation Checklist

### *Planning*

A program description should include:

- Mission statement
- Goals and objectives
- Activities to be conducted
- Resources to accomplish activities
- Stage of development and context
- Logic model

Work plans should include:

- Specific, time-framed goals
- Objectives for each goal
- Specific related activities
- Measures of success
- Time frame for goal achievement
- Team member responsible for goal

### *Evaluation*

Evaluation reports should include:

- Process and goal-oriented measures
- Quantitative and qualitative measures
- Stakeholder responses

## CHAPTER 3

# Composing a State EHDI Summary Report

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A summary report can be a useful tool for a state EHDI program by providing a clear, concise overview of the program for stakeholders and policy makers. A summary report can: summarize state EHDI program achievements, goals, and future objectives; provide key program information to administrators, state legislators, and other policy makers; raise public awareness of a state EHDI program (for example, reports can be posted on state websites); and provide an immediately available template to use when preparing other reports.

Because summary reports might be read by people who are either unfamiliar with an EHDI program, or have only a general understanding of the program, they should be written and organized in a way that will be easy to follow. A summary report is typically printed and bound, and often include graphics (pictures, diagrams, and such) to convey specific messages and strengthen the overall appearance of the report. For information about what types of statistical data can be included in an EHDI annual report, please refer to Chapter 4. Depending on the EHDI program, all of the suggested types of statistical data in Chapter 4 may not be appropriate to include in an annual report. A summary report also should include a description of the program, its goals, activities, achievements and challenges, a description of legislation and rules related to hearing screening (if applicable), program tracking system, stakeholders, and any other related components.

To determine the format and information that should be incorporated into a summary report, a comprehensive outline of suggested chapters and corresponding sections is provided. Differences between EHDI programs might mean that some reports will either not include all the suggested chapters/sections, or require additional chapters/sections to be included. To further assist in the development of a summary report, Internet links to previous reports prepared by CDC-affiliated programs are included at the end of this chapter.

## Cover

The cover page of the report should include the title, the year covered by the report, and the name of the state EHDI program. A program logo (if available) or other related agency graphics can also be included.

## Cover Letter

This letter serves as a preface to an EHDI summary report stating the intention(s) of the report and providing a very brief outline about infant hearing loss and the role of the state EHDI program. This letter can be from a health commissioner or other senior state government official.

## Contents

The contents page is a list of all the report chapters and sections, and their corresponding page numbers.

## Executive Summary

This should be a two-page, or less, summary that provides the reader with a brief overview of infant hearing loss and describes the role and activities of the state EHDI program. The status of EHDI related legislation, statistics related to the percentage of hospitals with Universal Newborn Hearing Screening (UNHS) programs and infants screened, and program goals and achievements should be included. Program challenges should also be mentioned.

## Program Overview

### *Background*

This section summarizes the importance and background of infant hearing loss and the purpose of a state EHDI program. The magnitude of the problem of infant hearing loss, developmental effects of undetected infant hearing loss, risk factors for infant hearing loss, and a brief history and explanation of the state EHDI program should be addressed in this chapter.

### *Legislation and Rules*

This chapter should specify whether the state has legislation, rules, or both regarding newborn hearing screening and intervention. If such legislation or rules are in place, this chapter should provide an explanation of them, including the year of enactment of each, requirements for data reporting by hospitals or providers, follow-up procedures and other relevant provisions. If legislation or rules are not currently in place, the chapter should detail whether passage or approval of such is anticipated.

### *Stakeholders*

This chapter should identify the organizations and people who have an interest in or support a state EHDI program (Appendix V provides examples).

### *State Advisory Board*

This chapter describes the advisory board and summarizes its activities. The number of board members and a summary of their professions should also be included. Whether the board is mandated by state legislation or rule(s) also should be cited.

## Program Summary

### *Program Description*

This chapter should explain in detail how the EHDI program is organized and how it functions, and should include the following sections (additional sections might be needed depending on the specific structure of a program).

### **Funding Sources**

This section should list and briefly describe, the funding sources for the state EHDI program, including awards, grants, or cooperative agreements, or a combination thereof.

### **Personnel**

This section should include the number of people currently working with the program, the amount of time each works with the program (that is, part or full time), and a brief job description for each position.

### **Integration**

This section should list, and explain the integration of an EHDI program with other state children's programs or services. It should include information about plans to integrate with other state agencies or organizations.

### **Goals, Activities, and Achievements**

This is one of the most important sections. It should explain clearly and concisely the programs intentions, activities, and accomplishments, and

impress upon readers the importance of the state EHDI program. The following type information can be included:

- A list or table of the program goals. If the program is using defined goals, such as the seven EHDI national goals described in Chapter 1, the program's status in relation to each goal, sub-goal or both should be described.
- Summarize program accomplishments, including references to results (that is, statistical data) that might be helpful.

## Program Tracking System

### *Tracking System*

This chapter summarizes how an EHDI program obtains and maintains EHDI-related information on infants and children to satisfy established follow-up procedures and goals. It should include sections addressing the following topics.

### Process Overview

This section should outline how the EHDI tracking and surveillance system works, or is intended to work. It should explain how screening, diagnostic, and intervention data (if applicable) are captured, as well as how key stakeholders (for example, healthcare providers, audiologists, EHDI program staff) interact with the system.

### Tracking System Description

This section should explain the intended function of system, and the technology, program or both used.

## Tracking System Status

This section should provide information on the timeline for the development and implementation of the EHDI tracking system and predict a completion date.

## Tracking System Evaluation

This section should comment on the current and predicted effectiveness of the tracking system, including plans to update or change the system.

## Data Items

This section should list the specific data items (for example, number of infants screened, referred for audiologic evaluation, etc.) collected by the tracking system. It also should include plans to change or expand the items currently collected. If the state does not collect data currently, list any items that are planned to be collected in the future.

## *Privacy and Confidentiality*

This chapter outlines the federal and state laws, rules, regulations, guidelines, or a combination thereof, that govern the reporting, access, and use of EHDI-related information by programs and individuals. It should include any special issues or conditions related to the privacy of EHDI information.

## *Statistical Reports*

This chapter includes all relevant statistics related to the performance indicators in the national EHDI goals, such as screening, referral, audiologic evaluation, follow-up and enrollment in early intervention statistics. Other relevant statistics include those about laterality, severity

of loss and late onset, progressive or acquired hearing loss (Chapter 4 provides additional information about statistics to include and examples of how to present these data). If statistical information is not available, the chapter should explain why not (if known), and when the data will be available.

### **Program Evaluation**

This chapter should summarize the findings from the most recently completed program evaluation, including the program's progress toward reaching its stated goals (Chapter 2 provides more information about program evaluation).

### **Public Awareness**

#### *Training, Education and Informational Materials*

This section should list and briefly describe any materials (for example, fact sheets, brochures, etc.), that are available to parents and families about infant hearing loss, newborn hearing screening and/or early intervention services. It also should explain how parents and families can obtain these materials.

#### *Website*

This section should describe the key features of a state EHDI website (if one is available), including the URL (website address), relevant notes about the site, and any planned changes. Any available information about the amount of use of a website is helpful. Refer to Chapter 5 for more information about creating and maintaining a state EHDI website.

## Challenges and Future Direction

### *Family Issues*

This section should highlight issues identified by the EHDI program, advisory board, parent comments, and any other relevant sources, describing how concerns will be addressed.

### *Challenges*

This section should make stakeholders and others aware of the specific issues that face the state EHDI program by describing current and future challenges the program faces, such as the lack of legislation, funding, or a reporting mandate.

### *Future Direction*

This section should outline any planned directions the state EHDI program intends to follow, based on the program's stated goals and objectives.

## Appendix

The appendix should include any other information considered useful and references to any published material, websites, organizations, or other sources that may offer additional relevant information.

## Online Annual Reports

The following are useful examples of annual reports. Please note we have no control over the content on these websites. Links to these sites are included for information only.

- HIV Counseling and Testing in Publicly Funded Sites: 1996 Annual Report

<http://www.cdc.gov/hiv/pubs/cts96.htm>

- Gonococcal Isolate Surveillance Project (GISP) Annual Report - 1998

<http://www.cdc.gov/ncidod/dastlr/gcdir/Resist/GISP98rep.pdf>

## State EHDI Summary Report Checklist

A summary report should include the following:

### *Cover*

- Title
- Logo
- Graphics

### *Cover Letter*

- Intentions of the State EHDI Summary report
- Written by a Commissioner or other senior government official

### *Table of Contents*

- Topics
- Page numbers

### *Executive Summary*

- Brief overview of infant hearing loss
- Status of EHDI related legislation
- Key statistics (such as, percentage of UNHS hospital)
- Program goals, achievements, challenges

### *Program Overview*

- Background, including magnitude of problem, effects of undetected hearing loss, risk factors, explanation of state program
- Legislation and rules
- Stakeholders
- State advisory board, members, professions, activities, mandate

## State EHDI Summary Report Checklist (*continued*)

### *Program Summary*

- Program description, organization, function
- Funding sources, grants, awards
- Personnel, time devoted to program
- Integration with other programs
- Goals, activities, achievements

### *Program Tracking System*

- Process overview, how system works, how data captured
- System description, technology
- System status, developmental milestones, completion date
- System evaluation, effectiveness of system, changes, updates to system
- Data items, specific items collected, plans to change, expand system

### *Privacy and Confidentiality*

- Laws, regulations, guidelines on reporting, access and use of information
- Special privacy issues

## State EHDI Summary Report Checklist (*continued*)

### *Statistical Report*

- Screening statistics
- Referral statistics
- Audiologic evaluation statistics
- Laterality and severity of loss statistics
- Follow-up and intervention statistics
- Late onset, progressive or acquired hearing loss statistics
- Other relevant statistics (e.g., number and percent of hospitals within the state that are considered UNHS hospitals; mean and median age at screening; mean and median age at diagnosis of hearing loss)

### *Program Evaluation*

- Findings from most recent program evaluation
- Progress towards stated program goals

### *Training, Education and Informational Materials*

- Brochures, fact sheets, etc.
- How materials obtained

### *Website*

- Key features, URL, planned changes
- Amount of use of site

## CHAPTER 4

# Statistical Reports for State-Based EHDI Screening, Referral, Audiologic Evaluation, and Follow-Up

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An annual statistical report is an important element of the state-based EHDI program. While the format for the report can vary depending on the preferences of the state, each report should summarize the annual public health accomplishments of the program for the year by synthesizing the annual screening, referral, evaluation, and intervention data into a format that readily describes the progress of the screening and tracking program. A report of this kind is invaluable, because it outlines the program's strengths and weaknesses, documents the incidence of hearing loss over time, and presents common measures that can be used to compare the state's tracking program to that of other EHDI states. These data might be of particular interest to stakeholders and legislators because policy decisions are made regarding EHDI screening and tracking activities. This chapter provides guidance for producing an annual statistical report. It should be noted that the following represents a comprehensive statistical report and may not be feasible for programs that are still in development. However, EHDI programs should strive to incorporate the following content when possible.

### Data Items

A primary goal of the annual statistical report is to facilitate a comparison of each year's program performance to the program objectives of the newborn hearing screening program's goals and objectives. Program goals and objectives that should be common to all newborn hearing screening programs are those detailed in the National EHDI Goals and Objectives (Chapter 1).

Some of the measurable objectives from the National Goals and Objectives document are surveyed by Directors of Speech and Hearing Programs in State Health and Welfare Agencies annually (see Appendix 1). Although these aggregate data are surveyed only once per year, CDC and the Joint Committee on Infant Hearing (JCIH) recommend that each measure be quantified on a monthly basis. Whether through figures, tables, or text, a state should measure its performance against each of the program objectives throughout the year and publish the results of these efforts at least once per year in an annual statistical report.

Completing the Annual Statistical Report Worksheet (Appendix IV) might be a useful step towards ensuring that a state's statistical report includes quantities that reflect progress towards each of the program objectives. Ideally, if the state does not yet collect data from which the indicators are calculated, the state should detail why these data are not being collected and any plans for the future collection of these data.

## Data Sources

CDC recommends that each state have a central EHDI tracking system for all its children and that the statistical report be based on summary statistics that are generated from this database. States that do not have central tracking systems for infants and children may include statistics from other sources, including summary statistics or counts reported by individual hospitals, individual health care providers (including audiologists), other sources (e.g., birth certificates), or a combination of these.

The report should detail the source of the statistical data and provide an estimate of the accuracy of the information by stating whether the data are estimates, counts, or a combination of both estimates and counts.

## Elements of the Statistical Report

An effective way to convey the key points of an annual statistical report is to preface each report with an executive summary. This summary typically begins with a very brief introduction and then details key summary statistics by topic. For example, an executive summary may begin with an overview of the changes in the state's EHDI legislation, funding, or philosophy followed by overall rates of screening, referral, audiologic evaluation, and intervention over the past year or years. Areas that a state wishes to highlight should be presented in the executive summary to draw attention to program successes and continuing challenges.

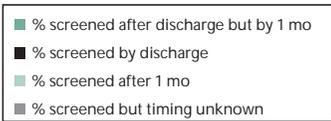
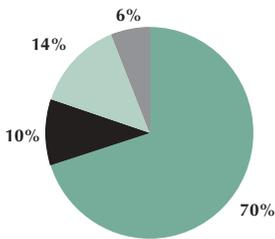
The body of the statistical report should detail relevant summary measures related to screening, referral, audiologic evaluation, and follow-up (intervention) data in text and/or graphical form. As a means of describing group differences, these statistics should be presented separately for relevant demographic groups, such as race, ethnicity, geographic region, and insurance type. Intra-group contrasts might be helpful especially when identifying specific challenges in the EHDI process across the state. Figures and tables should be used whenever appropriate to make the report more user-friendly for non-scientific readers, and to describe the program's progress over time.

Although frequency counts (e.g., the number of cases of hearing loss identified over a given reporting year) often convey valuable information related to EHDI performance, rates per 100 (%) or per 1,000 (e.g., the rate of hearing loss for a given reporting year) should be used when appropriate to standardize the statistics for comparison across time and across states. Because the EHDI system will contain confidential information, states must ensure that released data does not identify any individual (see Chapter 6). EHDI programs should research existing data release guidelines before publishing statistics or descriptive data of children with hearing loss. Specifically, state law or policy often regulates the minimum cell size necessary for data release to the public. These precautions are in place to protect the privacy of individuals and families and it is the responsibility of the EHDI system to ensure that data are consistent with such regulations.

When presenting summary statistics graphically, pie charts might be most appropriate for those statistics calculated from a single year of data (Figure 1), whereas histograms and bar charts might better contrast trends in these same measures over time (Figure 2). States with many years of data might consider more creative methods of data presentation when presenting time trends.

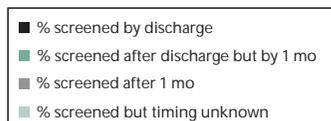
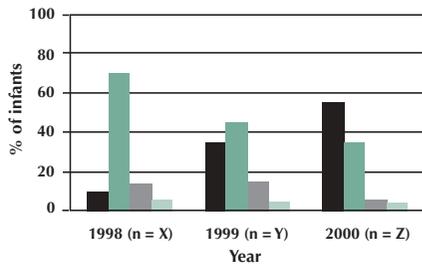
**Figure 1**

Timing of Hearing Screening (2000)



**Figure 2**

Timing of Hearing Screening by Year



Much of the content included in the statistical report will depend on the developmental stage of the EHDI screening and tracking program. At minimum, states should endeavor to include a summary of statistics related to the following program activities: screening; referral for audiologic evaluation; diagnostic evaluation; intervention; and loss to follow-up.

### Screening

Summary statistics should include the number and percentage of infants who are screened before discharge, who are screened before one month of age, and whose guardian’s declined newborn hearing screening. The

number and percentage of infants who did not pass the determinative hearing screen and the number and percentage referred for audiologic evaluation should also be presented. Ideally, these screening rates should be reported separately for those infants born outside of a hospital and those born out of state. The total number of live births for the state for the given year should be included in the table of screening statistics and used as the denominator in the calculation of all screening rates.

This section also should include a summary of the number and percentage of hospitals in the state that screen at least 98% of infants before discharge and, if applicable, the number and percentage of small hospitals that are exempt from universal newborn hearing screening, but that have a protocol in place for referral to an active newborn hearing screening program.

### *Referral and Audiologic Evaluation*

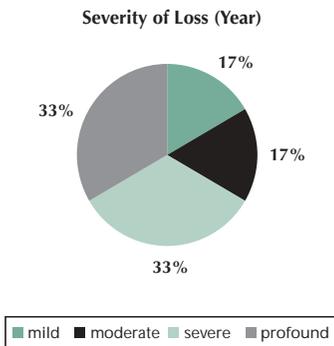
Similar to reporting screening statistics, a summary table(s) or graphic(s), or both, of referral rates and performance should be generated. The summary should include the number and percentage of infants who were screened and did not pass the determinative screening protocol, referred for an audiologic evaluation, and referred and actually received the audiologic evaluation before 3 months of age. Information on the number and percentage of infants referred for audiologic evaluations among those who were not screened for hearing loss should be included, as should the number of cases of hearing loss identified through audiologic evaluation. A state-based rate of permanent childhood hearing loss (PCHL) should be reported.

The rate of PCHL may be reported both with and without the mild cases of hearing loss included in the numerator of the calculation if eligibility for services differ by degree of loss. The appropriate denominator to be used in these calculations will depend on the state's rates of screening and loss to follow-up. States should consider and provide justification for using a specific denominator (e.g., number of live births, number of infants screened at birth, etc.).

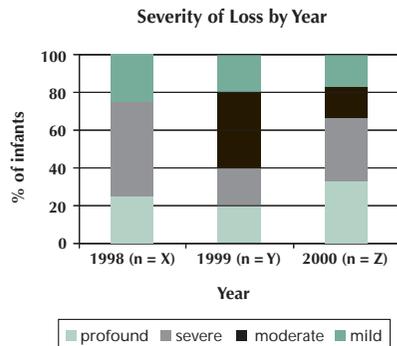
### Laterality and Severity of Loss

The distribution of hearing loss severity should be reported in the statistical report for all cases combined (number and percentage), for cases of unilateral hearing loss (number and percentage), and for cases of bilateral hearing loss (number and percentage). Incidence rates also should be presented documenting the distribution of hearing loss severity (in decibels). The total number of confirmed cases of hearing loss should be included in each of the tables and histograms related to the laterality and severity of the confirmed cases of hearing loss (as allowed by state law). The following figures (Figures 3 and 4) can be used to depict the distribution of hearing loss severity.

**Figure 3**



**Figure 4**



### Follow-up and Intervention

Include tables or figures, or both, that quantify the total number and percentage of children diagnosed with hearing loss who were referred, and who received appropriate intervention services before and after six months of age. Further, the number and percentage of eligible infants/children who had a signed IFSP (or an equivalent intervention plan) by 6 months of age, and the number and percentage of identified cases of

hearing loss whose guardians refused intervention should be quantified. States with more comprehensive statistics on intervention and follow-up should report the number and percentage of families of children with hearing loss that received family support information about early intervention services, whose care is coordinated between the medical home and related professionals, and the number/percent of infants identified with hearing loss who were referred to medical specialists (otolaryngologists, ophthalmologists, geneticists, etc.). The number and percentage of infants who were lost to follow-up after a hearing loss was confirmed should be reported in this section as well. If sufficient data exist, statistics should be reported by hearing loss severity group (mild, moderate, moderately-severe, severe, and profound).

### *Late Onset, Progressive or Acquired Hearing Loss*

Because PCHL might be identified after infancy via tracking cases with high risk indicators, it is important to report statistics related to late onset, progressive, or acquired hearing loss. The statistical report should include the number and percentage of infants with one or more risk factors for acquired hearing loss, and the number and percentage of infants with risk factors for acquired hearing loss that were re-screened by 3 months, 6 months, and annually thereafter. Finally, the number and percentage of infants and children identified with acquired hearing loss should be documented.

### *Other Relevant Statistics*

The annual statistical report should tabulate the number and percentage of hospitals within the state that are considered Universal Newborn Hearing Screening (UNHS) hospitals. In every case, the state-based definition for UNHS should be provided. Other suggested statistics to be reported include the mean and median age at screening and the mean and median age at diagnosis of hearing loss. Standard deviations should accompany all mean estimates.

## Dissemination of the Report

CDC recommends that each annual statistical report be disseminated widely to appropriate audiences, including fellow researchers, clinicians, legislators, advisory committee members, parent groups, and the general public. Distribution of this report within the state health department can encourage collaboration with other departments by fostering inter- and intra-departmental communication. Although it is suggested that the statistical report be formally published, it is also recommended that the report be posted on the state's website. Further, highlights of the full statistical report should be published in the summary report (Chapter 3), which presents a comprehensive overview of the entire state EHDI program.

## Statistical Report Checklist

A statistical report should include:

### *Summary*

- Executive summary of key statistics by topic, including performance indicators to be highlighted

### *Graphics*

- Pie charts, when appropriate
- Histograms, when appropriate

### *Statistics*

- Screening statistics
- Referral statistics
- Audiologic evaluation statistics
- Laterality and severity of loss statistics
- Follow-up and intervention statistics
- Late onset, progressive, or acquired hearing loss statistics
- Other relevant statistics (e.g., number and percentage of hospitals within the state that are considered UNHS hospitals, mean and median age at screening, and mean and median age at diagnosis of hearing loss)



## CHAPTER 5

### Creating an EHDI Website

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Raising public awareness about the benefits of detecting hearing loss early in life and the positive outcomes of early intervention programs for children with identified hearing loss is key to the success of state- and territory-based EHDI programs. Promoting EHDI programs increases the demand for EHDI services, and enhances the long-term outcomes of children diagnosed with hearing loss, and their families. Although resources often limit state health departments from implementing multimedia public health awareness campaigns, public health messages can be delivered to a variety of audiences in a diverse number of ways.

One of the simplest and most cost efficient ways to raise public awareness about EHDI is to develop a state or territory EHDI website, an essential part of any modern public awareness campaign. Many people use the Internet to find information about a wide variety of topics, including infant hearing loss, family support services, and communication options. Creating and maintaining an EHDI website is also an effective way to:

- Provide information about activities and services provided by the state EHDI program.
- Inform the public about current, pending, or proposed EHDI legislation.
- Reach a wide variety audiences (public, partners, advocacy groups, legislators, academia).
- Update information on a regular basis.

In addition to raising awareness about a new or developing state EHDI program, a website can complement the activities of a more established EHDI or related healthcare program. Annual reports, brochures, and fact sheets can be distributed easily and cost efficiently through the website, minimizing the time required by program staff to provide general

information to the public. For programs currently without a website, the following will provide some general information about important things to include, and how to design and set up a website. Ideas and suggestions about items that can strengthen an existing website are denoted by the phrase (*update item for existing websites*).

The following suggestions for creating and maintaining an EHDI website are grouped into content and design sections. The content section provides examples of the type of information that is useful to include in a state EHDI website. The design section provides suggestions on how to organize information and create a theme for a website. It is important to remember that a website should be reviewed and updated on a regular basis. Please note that before developing or modifying a website, the designated state regulatory department or equivalent (if applicable) should be contacted to ensure any state requirements for websites are met. In some states a regulatory department might even be the group that is required to develop and maintain an EHDI program website.

## Content

The content of a website should clearly convey the intended message of the program. Content needs to be clear, complete, and compelling. It should also be developed before the design of any web pages because different computers can display websites in a variety of ways. This means the content should be able to convey the intended message without the use of graphics or other related items. The reading level of the audience should also be considered during the development of website content. Many different people access the Internet and using simple terms will help ensure all audiences will be able to understand the content. For examples of simple terms, visit the “Plain Language” website:

*<http://www.plainlanguage.gov/library/smpl1.htm>*

The following is a general list of sections to include when developing an EHDI website for the first time, or updating an existing website. These

suggested sections are intended only as a guide, and sections should be added or deleted as appropriate. Some of the suggested items to include are based on recommendations from Chapter 3 on composing a state EHDI summary report. A list of EHDI-related websites are included in Appendices VI and VII for reference purposes. Information specific to each state EHDI program that may be helpful in developing a website can be found at:

- 1) Online CDC EHDI State Profile: [www.cdc.gov/ncbddd/ehdi/state\\_profile/](http://www.cdc.gov/ncbddd/ehdi/state_profile/)
- 2) National Center for Hearing Assessment and Management (NCHAM): [www.infanthearing.org/states/index.html](http://www.infanthearing.org/states/index.html)

### *Overview of the Problem*

The website should include background on the issue of infant hearing loss (for example, prevalence rates), and the potential problems that stem from an undetected hearing loss (for example, delayed language development). Information about the common causes of hearing loss, such as infections and genetic factors also should be included (*update item for existing websites*).

### *EHDI Explanation*

Because some people will be unfamiliar with an EHDI program, it is a good idea to define EHDI and the primary goals and activities of the program (for example, screening, audiologic evaluations, enrollment in intervention services).

### *Recommendations*

Current recommendations regarding hearing screening, evaluation, and intervention (for example, Joint Committee on Infant Hearing recommendations) should be outlined.

## *Current Status*

The status of hearing screening and the other components of the EHDI processes should be explained briefly. Information about newborn hearing screening and intervention legislation, or rules or both, such as year of enactment, provisions of the bill (for example, whether all hospitals are required to screen newborns and whether the state provide funds to pay for any screenings) and number of hospitals providing Newborn Hearing Screening should be included.

## *State EHDI program*

This section should provide an overview of the state programs:

- Organization — the agency or department that the EHDI program is a part of and any other information deemed relevant (*update item for existing websites*).
- Goals — both the short and long-term goals of the state program.
- Accomplishments — describe any brochures, manuals, conferences, or products that the state program has been involved in designing, producing or both.
- Grants/research — grants, cooperative agreements, funding for research or other awards.
- Data system — how screening, diagnostic and intervention information is gathered and updated (*update item for existing websites*).

## *Future Plans*

The future direction of the state EHDI program should be outlined and an idea of what to expect from the state program in the coming months and years provided (*update item for existing websites*).

## Data

If available, data such as hearing screening rates and the number of cases identified should be included.

## Additional Resources

Electronic versions of reports, brochures, fact sheets and a list of pediatric audiologists should be included (*update item for existing websites*).

## Links

A list of Internet links to other state, national, or other websites that might be helpful to people wanting more information should be included. When listing Internet links to other organizations or groups it is advisable to include a disclaimer at the beginning of this section to inform people that the state website does not have any control over the content on these other sites. Following is an example of such a disclaimer:

*We have no control over content on outside websites. Links to these sites are included for information purposes only. The views and opinions expressed at other sites are not necessarily those of (insert name of the state program and agency here).*

## Current Events

This is an optional section where copies of or links to EHDI-related articles can be placed. This can be an effective way to provide up-to-date information to parents and others about progress in hearing loss detection and intervention options (*update item for existing websites*).

## *What's New/Announcements*

This section gives a brief update of new items added to a state website and provides any relevant information about upcoming meetings or events related to EHDI (*update item for existing websites*).

## *Contact Information*

Contact information, including an e-mail address, for either the state EHDI program or a person who can respond to questions about the program should be listed.

## **Design**

For the purposes of this chapter, design refers to the organization and visual appearance of a website. While the primary purpose of an EHDI website is to provide useful information about infant hearing loss and the role of a state EHDI program, this information should be presented in a logical and visually appealing way to encourage website use. The following suggestions are intended as a guide, and are not meant to restrict the use of additional elements (such as colors or graphics for example). A list of EHDI-related websites is included in Appendices VI and VII for reference purposes.

## *Organization*

It is vital to organize website information in a logical and easy-to-find format. If people cannot find the information they want, they might not use the Website. To help make it easier, organize information by topic, grouping related information together under a few main topic headings. These topic headings should be selected to reflect the needs and interests of stakeholders in the EHDI program. Information can be organized by: type of information (for example, facts about hearing loss or program

information), audience (for example, parents, physicians, other professionals) or by both type and audience (for example, Topic 1: Facts about hearing loss and Topic 2: Screening guidelines).

## *Visual Appearance*

Suggestions to keep in mind when creating the visual appearance of a state EHDI website include the following:

### **Color Scheme**

A theme of two or three main colors should be used in logos, headings, text, and any other items. A random mix of multiple colors creates a site that is confusing and therefore, ineffective. If a state program already has a color scheme used in a logo or in brochures, posters, or other published materials, the same scheme should be used for the website. Colors that are easy to read and convey the intended message should be selected.

### **Graphics**

Pictures and other graphics that capture viewer attention, compliment and reinforce text messages, and increase understanding of practices associated with EHDI (e.g., showing screening equipment) should be included. While graphics can be used to help explain or express certain concepts, too much of a good thing can overwhelm the viewer and reduce the impact of the information. While there is not a set rule regarding the number of graphics on a single website page, four to six are sufficient, depending on the exact layout of the web page (a website can be made up of multiple different pages, a new page typically appears when a link on a web page is followed). Graphics relevant to an EHDI website include pictures of infants undergoing hearing screening, children participating in intervention services and program logo(s).

***Note:** Pictures used on a website require permission from the people shown, or the organization from which the picture was obtained, or both. For pictures taken by EHDI staff members, a signed consent form from the person(s) in the picture will usually suffice. Images taken from other websites, publications, or organizations will require documented consent before they can be used. The appropriate office or department in the state health department should be contacted for further information and clarification.*

## Text Appearance

An important but often overlooked element in website design, is the size and style of font used. Certain font types are easier to read than others. Large blocks of sans serif or italic font styles are hard to read, and they are better used for headings and cut lines under pictures. Font size can have a large effect on whether text attracts a viewer's attention. Body type should be no smaller than 10 point, with 12 point being preferred by older readers. Headings are best in the 14-16 point range. As a general rule, no more than three type sizes or fonts should be used on a page.

## Accessibility

Information on a website should be accessible to all audiences, including those with disabilities. Section 508 of the Rehabilitation Act was enacted in part to eliminate barriers in information technology and to make available new opportunities for people with disabilities. While Section 508 applies to federal agencies, review of the standards will help to ensure an EHDI site is accessible to all audiences. The Section 508 website has more information and can be found at:

<http://www.section508.gov/>

## EHDI Website Checklist

### *Content*

Content components include:

- Terms suitable for all audiences
- Overview of the problem
  - Background on infant hearing loss
  - Potential problems of infant hearing loss
  - Information on common causes of hearing loss
- EHDI explanation
  - Primary goals of the program
  - Basic program activities
- Recommendations regarding screening, evaluation and intervention
- Current status
  - Status of screening and other processes
  - Legislation
  - Number of hospitals providing screening
- Program section
  - Organization, agency or department affiliated with
  - Goals, short- and long-term
  - Accomplishments, materials or products designed
  - Grants or research
  - Data system, how information is gathered and updated

### EHDI Website Checklist (*continued*)

- Future plans
- Data
  - Screening rates
  - Number of cases identified
- Additional resources
  - Reports, brochures, fact sheets
  - List of pediatric audiologists
  - Links to relevant websites (include disclaimer about other websites)
  - Current events
  - What's new/announcements
  - Contact information
  - Simple terms and phrases

### *Design*

Design elements include:

- Organization
  - By topic
  - Related topics grouped together
- Color scheme
  - Two or three main colors
  - Same as in logo
  - Easy to read

### EHDI Website Checklist *(continued)*

- Graphics
  - Relevant charts or graphs
  - Relevant pictures
  - Permission for use of picture
  - No more than four graphics per page.
- Text appearance
  - Easy to read type face
  - No large blocks of sans serif type
  - Body type 10-12 point size
  - Headings 14-16 point size
  - No more than three type sizes/faces per page
- Accessibility (review Section 508 standards)



## CHAPTER 6

# Privacy and Confidentiality of Data

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State EHDI programs are responsible for developing policy and procedures that walk the fine line between protecting the privacy of an individual and providing appropriate access to information. This chapter provides an introduction to the legal, social, and ethical aspects of privacy and confidentiality, and the need for public health access to personal information. Privacy issues touched on here include confidentiality, informed consent, and security (particularly in electronic data transmission). Because these terms are used in various ways, definitions of terms used in this document are provided. Privacy-related policy and law is a rapidly evolving field. Users are urged to expect, and follow, changes at both state and national levels. Refer to the Resources and References section of this chapter for sources of more in-depth information.

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### Definitions of terms as used in this chapter

**Confidentiality:** Confidentiality means that information is disclosed or maintained with the expectation that it will not be divulged to others, and will be handled in ways that are consistent with the original stated purpose.

**Covered Entity:** Health plans; healthcare clearinghouses; healthcare providers who conduct certain financial and administrative transactions electronically . . . such as electronic billing and fund transfers.

**Protected Health Information:** Individually identifiable information that is a subset of health information, including demographic information collected from an individual and: 1) is created or received by a healthcare provider; 2) relates to the past, present, or future physical or mental condition of an individual.

**Public Health Authority:** Section 164.501 (2) (iii)- Public Health Authority, means an agency or authority of the United States, a state, a territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including employees or agents of such public agency or its contractors or persons or entities to whom it has granted such authority, that is responsible for public health matters as a part of its official mandate.

**Public Health Activity:** Section 164.512(2)(b)(1)(i) Public Health Activities: preventing or controlling disease, injury, or disability, including, but not limited to the reporting of disease, injury, vital events such as birth or death, and the conduct of public health investigations, and public health interventions.

**Privacy:** Privacy is the legal right of individuals to be let alone, and to restrict access to information about them by third parties. An Institute of Medicine report states that the term privacy can include three interests: 1) autonomy, or decisional privacy, which protects fundamental constitutional liberties related to private behavior; 2) protection against surveillance or intrusion where there is an expectation of privacy, for example, protection against unlawful searches; and 3) informational privacy, which concerns “the interest of the individual in controlling the dissemination and use of information” about oneself.

**Informed Consent:** Informed consent as defined for the purposes of Medline indexing is “the voluntary authorization, given to the physician by the patient, with full comprehension of the risks involved, for diagnostic or investigative procedures and medical and surgical treatment.” Few newborn screening programs require consent by parents after a systematic “informing” process. A number of programs recommend a “decline only” adaptation in which a parental decision not to have screening is documented and a decision to have screening is not documented.

**Security:** Security means the technical and administrative procedures are designed to protect data systems against unwarranted disclosure, modification, or destruction.

**Electronic transmission of health information:** This refers to health information that is housed electronically and/or is transmitted over telecommunications systems/networks. The Health Insurance Portability and Accountability Act, “HIPAA”, mandates new security standards to protect an individual’s health information, while permitting the appropriate access and use of that information by health-care providers, clearinghouses, and health plans. HIPAA also mandates that a new electronic signature standard be used where an electronic signature is employed in the transmission of a HIPAA standard transaction. All electronic formats (including Web-based transmission) are subject to HIPAA regulation. Data in hard copy is excluded from the Data Security provisions of HIPAA, but not from the Privacy Rule provisions in HIPAA.

**Education Records:** The Family Educational Rights and Privacy Act, (FERPA) 20 USC 123(a)(4) defines an education record as those documents that are directly related to a student and maintained by an educational agency or institution or by a party acting for the agency or institution. Please note that educational records are an issue of who possesses the documents, not really what they contain, and there are some exclusions that are not of relevance to EHDI programs

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The development of state-based EHDI policy and procedures is typically done with the guidance of appropriate authorities in state government. This chapter is intended only as an orientation for EHDI staff to the major issues that must be addressed and point out the legislative and other determinants that are commonly considered as policy and procedures are developed and updated. The chapter provides an overview of the following issues: 1) Federal privacy legislation, including the Privacy Act of 1974, the Freedom of Information Act, HIPAA, and Family Educational Rights and Privacy Act (FERPA); 2) state legislation mandating EHDI activities; and 3) social and ethical issues (including informed consent).

## Federal Legislation as a Model for State Legislation

State EHDI program staff must understand the balance between the public's right to information and the individual's right to privacy. At the federal level, the laws discussed in the following paragraphs determine what information can and cannot be released, and to whom it can be released. Basic awareness of these laws is important to the EHDI program because some of these laws directly affect the program's ability to collect data. Some of these laws, such as the Freedom of Information Act and the Privacy Act, affect only information collected or held by the federal government. However, EHDI programs need to be aware that each state has versions of these laws that either mirror or closely resemble the federal laws that could affect EHDI programs. Furthermore, it might be useful for state EHDI program staff to remember that state laws usually have the same or similar titles as their federal counterparts.

### *Federal Freedom of Information Act (FOIA)*

The Freedom of Information Act (FOIA) is the federal law that empowers the public, media, attorneys, and individuals to request information held by the federal government that is not related directly to them. FOIA applies to documents held by agencies of the executive branch of the

federal government and requires these agencies to make all information not specifically exempt from disclosure available to the public upon request. The fundamental public policy behind this law is twofold: first, government should not operate in secret; and second, the data should be available to the public who have paid for it. All states and some localities have passed laws similar to the FOIA that allow people to request access to records held by government. While the federal law has 12 exceptions, state exceptions vary. Most state laws have a medical records exemption in their FOIAs which does not permit an individual to access medical records other than his or her own.<sup>5</sup> Some states have more exceptions than the federal law, and give more guidance in the law about the application of the exceptions than the federal law does.<sup>6</sup>

### *Federal Privacy Act of 1974*

Federal agencies that are subject to FOIA are also subject to the Privacy Act of 1974, which protects individuals from having information that is collected for lawful purposes by federal agencies from unlawful disclosure and uses. The Privacy Act allows a citizen to know how these records are collected, maintained, used, and disseminated. An individual can gain access to most of the personal information about him/herself, and seek changes of inaccurate, incomplete, untimely, or irrelevant information. The Privacy Act does not apply to records maintained by state and local governments, or private companies or organizations. Again, most states have privacy laws which apply to state and local governments collecting data on citizens. In most cases, the state laws in this area are significantly more protective of privacy than the federal law.

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<sup>5</sup>See Official Code of Georgia §50-18-73, (2002) *Inspection of Public Records*.

<sup>6</sup> See NY CLS Pub O §86, Article 6, *Freedom of Information Law*, NY. (2002). This law has specific provisions under section 8 which declare that state funded hospitals are “agencies” of the state, and therefore required to comply with the Freedom of Information Law of NY.

## *Health Insurance Portability and Accountability Act of 1996 (HIPAA)*

The HIPAA Privacy Rule provides a floor of standards for privacy that can be made more stringent by state law. The Privacy Rule covers the privacy of personally identifiable health information (known as “protected health information”) sent or stored electronically by “covered entities”<sup>7</sup>, primarily health providers, health maintenance organizations, and health insurance companies. (The legal interpretation of HIPAA is the responsibility of the Office of Civil Rights in the US Department of Health and Human Services.)

Generally, a covered entity may not use or disclosure protected health information without valid authorization from anyone other than the individual affected, except for the purposes of treatment, payment, or healthcare operations. Although EHDI programs are not covered entities, their data sources are. Therefore, a basic understanding of the Privacy Rule is important for effective data collection. The Privacy Rule has a “public health exemption” that permits the electronic transmission of personally identifiable health information for public health purposes. Although EHDI data are HIPAA exempt once transmitted to state health departments, the same data may not be exempt when used in other settings. Therefore, EHDI program staff need to be sensitive to the Privacy Rule implications their collaborators face.

### *HIPAA Privacy Rule and Public Health*

A covered entity may use or disclose protected health information without the written authorization of the individual in the specific instances cited in the applicable section. Specifically, §164.512, “Uses and disclosures for which an authorization or opportunity to agree or object is not required” of the Privacy Rule (of HIPAA) has two specific exemptions that apply to the EHDI program.

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<sup>7</sup>See Definitions section for precise definition.

First, subsection (a) permits a covered entity to disclose protected health information to the EHDI program if a state has an existing EHDI reporting law or regulation, or subsequently enacts one.

Second, subsection (b) permits a covered entity to disclose protected health information to a public health authority that is authorized by law “to collect or receive protected health information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the report of disease, injury, [and] vital events such as birth or death”.<sup>8</sup>

The most significant distinction to make is that subsection (a) is for reporting required by law; and subsection (b) is for reporting authorized by law. Although there is no definition of “authorized by law” in the Rule, HHS sought to make this point more clearly in the Preamble to the Rule (64 CFR page 59929) and it reads:

When we describe an activity as “authorized by law,” we mean that a legal basis exists for the activity. The phrase “authorized by law” is a term of art that includes both actions that are permitted and actions that are required by law.

Understanding this distinction could be very useful in the event that a data source, such as a hospital is reluctant or refuses to provide data to an EHDI program that does not have a state reporting law, or an agency regulation mandating or permitting the data collection. There have been cases reported to the CDC where certain hospitals and clinics have turned away data abstractors because they did not understand the public health provisions in the Privacy Rule. The data sources wrongly believed that without a specific reporting law the data collection could not occur. Education on the Privacy Rule is necessary for all individuals involved in using or disclosing protected health information.

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<sup>8</sup> See §164.512(b) for complete provisions of this law. This section is included in the appendix of this manual.

Compliance with HIPAA standards will likely be required for EHDI data used for Medicaid or other insurance reimbursement. Regulations for privacy and electronic transmission are being developed on two separate tracks. Developments can be followed on the Internet, such as the Administrative Simplification Web site (see Resources and Reference section at the end of this chapter). As of January 2002, the privacy rule is due to be implemented in April 2003 for most “Covered Entities”, and the standards for electronic transmission is expected to be implemented in October 2002. However, Congress passed a law in December 2001 allowing covered entities to request an extension to the transaction standards and code set implementation. The Department of Health and Human Services (DHHS) website has more information on how to make an extension request.

### *Family Educational Rights and Privacy Act of 1974 (FERPA)*

FERPA protects the privacy rights of students and parents, and applies to all education records maintained by education agencies and institutions that receive federal funds in educational settings. FERPA requires written parental consent for the release of education records. EDHI program staff need to understand the possible obstacles that FERPA will raise in the referral and follow-up of those children who screen positive for hearing loss. Children identified with hearing loss are usually referred to some type of state early intervention service. In some states the early intervention services are either run or funded by the Department of Education, which must comply with FERPA. In these instances, FERPA can be a hindrance to an EDHI programs’ ability to track such children because FERPA restricts access to their records once they are in the Department of Education.

While FERPA generally prohibits access to education records without the prior written consent of the parent or guardian, there are two exceptions in FERPA which may allow public health authorities or their grantees or contractors access to educational records. The first exception allows access or disclosure of the education record to school officials with a

legitimate educational interest in the record. The second is granted to organizations conducting certain studies for or on behalf of the school to improve instruction. There are many ways that the schools can work with public health officials and CDC grantees to improve the outcomes for children identified with hearing loss, but they must first be found.

## State Legislation Mandating EHDI Activities

State mandates for screening can make it easier for EHDI programs to carry out important activities that otherwise might be challenged. Some state laws mandate that all newborns be screened for hearing in the birthing hospital. Some states mandate that newborn hearing screening and diagnosis be reimbursable (such mandates would not apply to ERISA insurance plans since they are exempt from state law—see endnote on ERISA).

State legislation can specify that EHDI programs have authority to access personally identifiable EHDI-related information, and/or stipulate that persons who provide information to the state in accordance to the legislation are held harmless. These approaches lessen the apprehensiveness of healthcare providers, which can be a barrier to their participation in EHDI programs. (See the Resources and References section of this chapter for more information on state legislation.)

## Social and Ethical Issues

EHDI programs have social and ethical implications that are often not directly addressed in legislative mandates. An implicit social and ethical goal is to implement EHDI program activities in a manner responsive to the needs and sensitivities of all constituencies. When the needs of various constituencies appear to be at odds, an advisory group can help develop acceptable approaches, and/or use its political position to help negotiate necessary compromises.

## Informed Consent

Informed consent, as defined for the purposes of Medline indexing, is “the voluntary authorization, given to the physician by the patient, with full comprehension of the risks involved, for diagnostic or investigative procedures and medical and surgical treatment.”

Few newborn screening programs require a systematic informed consent or disclosure process. A number of programs do recommend a “decline only” or “opt out” option, in which only a parental decision not to have screening is documented. Although this approach is less time consuming, the quality of such “informed consent” has been questioned.

General public concern about governmental intrusion into personal privacy and breaches of confidentiality have prompted recommendations that parents also be informed about tracking systems to ensure appropriate follow-up in the screening process.

## Data Release and Suppression Issues

State health departments are responsible for ensuring the confidentiality of the data they collect or maintain. As states develop tracking and surveillance systems, they will need to address a variety of confidentiality issues. While state EHDI programs may not be familiar with some of the following discussion, it is important that they understand the issues, to ensure the identity of individuals is protected, while maximizing the amount of information released. The EHDI system that states are developing is rich in information that will be useful to a range of public health activities. The data system will contain not only confidential, identifiable variables (such as name and address), but also a set of variables (date of birth, residence, birth weight) that, when used together, could identify an individual. Therefore, one of the major issues is how the information in the system will be released to key stakeholders and the public.

In the past, data confidentiality issues were often addressed by only releasing aggregate data, and simply suppressing “small numbers” in a data table. Often, a “rule of three” or a “rule of five” was used, whereby, if the number of cases in any cell of a table was smaller than the threshold number, the data were not shown. Additional data in the table might also have been suppressed to prevent calculation of the suppressed cell from the table’s rows and columns. This procedure would protect the data in the specified table. However, over several years or numerous data releases, the suppressed number had the potential to be inadvertently revealed.

Today, states are facing more challenges. More data are available, both within the state and in the private sector. States are making data available in microdata sets, as well as in data files that can be queried over the Web. More sophisticated and complex disclosure techniques are being used to address the ever increasing complex challenges regarding data confidentiality. Some of the more common disclosure protection techniques include: top-and-bottom coding, collapsing response categories, altering data through swapping, adding “random noise”, applying multiple imputations, and using more complex statistical techniques in cell suppression.

As the state EHDI programs establish their own data tracking and surveillance systems, they will need to develop data release policies to ensure protection of the confidentiality of the data they maintain. Many states regulatory agencies already have a data release policy. Some states may have convened data disclosure review boards. The EHDI program should review any existing policies and procedures to ensure they are current with today’s technology, and address any specific programmatic concerns. It is important to have a policy in place as data are collected, and to release data consistently within the boundaries of the policy. An EHDI program does not want to appear “arbitrary” in the rules it applies when releasing information.

There are numerous resources available that address current data protection techniques, as well as identify common threats to confidentiality and individual privacy. Following are a few resources that programs might want to use in reviewing or establishing their data release policies. The list includes selected key references.

1. Confidentiality, Disclosure and Data Access: Theory and Practical Applications for Statistical Agencies, eds. P. Doyle, J. Lane et al., U.S. Bureau of the Census, Washington DC, USA.

<http://www.elsevier.com/inca/publications/store/6/2/2/1/2/9/index.htm>

**Description:** There is a fundamental tension at the heart of every statistical agency mission. Each is charged with collecting high quality data to inform the national policy and enable statistical research. This necessitates dissemination of both summary and microdata. Each is also charged with protecting the confidentiality of survey respondents. This often necessitates the blurring of the data to reduce the probability of the reidentification of individuals. The trade-off dilemma, which could well be stated as protecting confidentiality (avoiding disclosure) but optimizing access, has become more complex as both technological advances and public perceptions have altered in an information age. Fortunately, statistical disclosure techniques have kept pace with these changes. This volume is intended to provide a review of new state of the art techniques that directly address these issues from both a theoretical and practical perspective.

2. Subcommittee on Disclosure Limitation Methodology, Federal Committee on Statistical Methodology: Statistical Policy Working Paper 22—Report on Statistical Disclosure Limitation Methodology, May 1994.

[www.fcsm.gov/working-papers/wp22.html](http://www.fcsm.gov/working-papers/wp22.html)

**Description:** A review and evaluation of the statistical disclosure limitation techniques used by Federal statistical agencies can be found in the Federal Committee on Statistical Methodology's 1994 report, Report on Statistical Disclosure Limitation Methodology (Statistical Policy Working Paper [SPWP] # 22). In addition, SPWP # 22 contains a set of 12 recommendations to improve disclosure limitation practices.

3. Interagency Confidentiality and Data Access Group, Federal Committee on Statistical Methodology: Checklist on Disclosure Potential of Proposed Data Releases- July 1999.

[www.fcsm.gov/cdac/checklist\\_799.doc](http://www.fcsm.gov/cdac/checklist_799.doc)

**Description:** The checklist consists of a series of questions that are designed to assist an agency's Disclosure Review Board to determine the suitability of releasing either public-use microdata files or tables from data collected from individuals and/or organizations under an assurance of confidentiality.

4. L. Willenborg, and T. De Waal, Elements of Statistical Disclosure Control, Springer-Verlag, New York, 2001.
5. L. Willenborg, L., and T. de Waal, "Statistical Disclosure Control in Practice", Lecture Notes in Statistics 111, Springer-Verlag, New York, 1996.
6. G. Duncan, T.B. Jabine, and V. de Wolf, Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics, by Panel on Confidentiality and Data Access. U.S., 1993.
7. Association of Public Data Users, Of Significance, 2000.
8. American Statistical Association, Committee on Privacy and Confidentiality. [www.amstat.org/comm/](http://www.amstat.org/comm/)

## Endnotes

ERISA is an abbreviation for a federal law that governs all employee benefit programs, the Employee Retirement Income Security Act of 1974. Generally, health insurance coverage is covered by ERISA when purchased through work and/or when it is part of job benefits provided by employers. Major exceptions to this are 1) the employer is a government agency of some kind (like a county or city), 2) the insured person is the owner of the company or is self-employed, and 3) the employer is a religious organization.

## Resources and References

### **The Privacy Act of 1974 and the Freedom of Information Act**

*A Citizen's Guide on Using the Freedom of Information Act and the Privacy Act of 1974 to Request Government Records* (March 1999)

[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106\\_cong\\_reports&docid=f:hr050.106](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106_cong_reports&docid=f:hr050.106)

Department of Justice, Office of Information and Privacy

<http://www.usdoj.gov/oip/oip.html>

Links to web sources of information access and privacy can be found at:

<http://www.accessreports.com/links.html>

### **HIPAA**

Administrative Simplification (US Department HHS)

<http://aspe.hhs.gov/admsimp/>

Office for Civil Rights (US Department HHS)

National Standards to Protect the Privacy of Personal Health Information

<http://www.hhs.gov/ocr/hipaa/>

National Committee on Vital Health Statistics (US Department HHS)

<http://www.ncvhs.hhs.gov/>

CDC National Immunization Program; Privacy, Confidentiality, Security, and Legislation (US Department HHS)

<http://www.cdc.gov/nip/registry/pcs.htm>

Georgetown University, Institute for Health Care Research and Policy, Health Privacy Project

<http://www.healthprivacy.org/>

American Medical Association

<http://www.ama-assn.org/ama/pub/category/2806.html>

Phoenix Health Systems, HIPAA Advisory

<http://www.hipaadvisory.com/>

## **FERPA**

Department of Education

<http://www.ed.gov/offices/OM/fpco/ferpalist.html>

National Center for Education Statistics

<http://nces.ed.gov/pubs97/97859.html>

Department of Health and Human Services, Office of the Secretary.  
*Standards for Privacy of Individually Identifiable Health Information includes a Section on FERPA in Part 2.*

<http://www.hhs.gov/ocr/part2.html>

## **State Legislation**

National Center for Hearing Assessment and Management, State Legislative Activities (Utah State University)

<http://www.infanthearing.org/legislative/index.html>

American Speech-Language-Hearing Association

<http://www.asha.org/>

CDC National Immunization Program; Privacy, Confidentiality, Security, and Legislation (US Department HHS)

<http://www.cdc.gov/nip/registry/legsurv.htm>

Georgetown University, Institute for Health Care Research and Policy, Health Privacy Project

[http://www.healthprivacy.org/info-url\\_nocat2304/info-url\\_nocat.htm](http://www.healthprivacy.org/info-url_nocat2304/info-url_nocat.htm)

## Additional Information

1. N.A. Holtzman, R. Faden, A.J. Chwalow, S.D. Horn, “Effect of informed parental consent on mothers' knowledge of newborn screening”, *Pediatrics*. 1983 Dec;72(6):807-12. [PMID: 6685863].
2. PubMed Search using MESH Browser for combination of terms “Jurisprudence” (includes informed consent and confidentiality), OR “Ethics” AND “Neonatal Screening” gives most current literature indexed in Medline. Specific PubMed search address:

<http://www.ncbi.nlm.nih.gov:80/entrezquery.fcgi?term=jurisprudence%5BMESH%5D+OR+ethics%5BMESH%5D+AND+%22neonatal+screening%22%5BMESH%5D&Label=PubMed+Search&cmd=Search&db=PubMed>

## Privacy and Confidentiality Checklist

EHDI programs will need to be familiar with the following legislation:

- Federal Legislation/Regulations
  - Freedom of Information Act (FOIA)
  - Federal Privacy Act of 1974
  - Health Insurance Portability and Accountability Act of 1996 (HIPAA)
  - Family Educational Rights and Privacy Act of 1974 (FERPA)
- State Legislation
  - EHDI mandates
  - FOIA-type legislation
  - Laws governing informed consent, data gathering and data release



## CHAPTER 7

# EHDI Tracking and Surveillance System

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As states expand their EHDI activities, they will need to develop a computerized data system. States vary as to which agency is responsible for which component of the system. For example, in some states, hospitals are responsible for the follow-up of infants who do not pass the screening, while in other states, the Department of Health is responsible for follow-up. In any case, as more infants are screened, it is necessary that complete and accurate data be available.

EHDI activities can be divided into two major phases: those associated with screening, tracking, evaluation, and diagnosis and those which begin once a child is identified with hearing loss. To support and track information through these two periods, some states have formed or conceptualized two distinct databases, while other states have defined a single database with an expanded number of data items to cover the children with hearing loss. Either of these two approaches is acceptable, as long as the needed information is available. For the purposes of this and the next two chapters, the information needed to support EHDI activities throughout the two phases will be discussed as two, separate databases. It is important to keep in mind, however, that there must be linkage between these two databases so that together they form an integrated EHDI Tracking and Surveillance System.

**Disclaimer:** Use of trade names is for identification purpose only, and does not represent endorsement by the Centers for Disease Control and Prevention, the U.S. Department of Health and Human Services, or the U.S. Public Health Service.

## Databases for Early Hearing Detection and Intervention

There are two types of databases used in EHDI: 1) Infant Hearing Screening Tracking Databases, which track infant hearing screening, referral and evaluation; and 2) Hearing Loss Registry Databases, which track follow-up of infants and children with hearing loss. The two databases are considered separately because the data in each are quite different, and often screening and intervention are carried out by different operational units within state government.

### Requirements for Infant Hearing Screening Tracking Database

Infant Hearing Screening Tracking Databases:

- Use data fields to track hearing screening procedures and results for each infant;
- Receive data on infant screening test results;
- Receive data on audiologic test results;
- Compare infants in the database with those in the birth registry;
- Check for duplicate records on the same child;
- Identify children who need hearing screening, rescreening, referral, or evaluation;
- Identify children with risk factors who need repeat hearing screening;
- Notify parents and healthcare providers of infants' need for screening and follow-up;
- Notify state health department case workers of infants who require screening or follow-up;

- Create summaries of hearing screening results and follow-up for each child;
- Create summary statistics for infant hearing screening programs.

## Requirements for Hearing Loss Registry Database

Hearing Loss Registry Databases:

- Use data fields to track early interventions received by family and child;
- Use data fields to track type, severity and laterality of hearing loss of each child over time;
- Use data fields to track language development and other developmental milestones;
- Receive data on audiologic test results;
- Receive data on medical, genetic and other test results;
- Receive data on interventions provided;
- Receive data on language development level and developmental milestones;
- Identify automatically children who are behind in needed intervention services;
- Notify state health department case workers of infants who need additional services;
- Create summary of hearing loss status, interventions, and language development for each child;
- Create summary statistics for early intervention program.

## Entering data into the Infant Hearing Screening Tracking Database

The purpose of the Infant Hearing Screening Tracking Database is to ensure that all infants born in a state will receive a hearing screening test and necessary follow-up. The database should, therefore, start with a roster of all newborns in the state. Since all births have to be registered and all infants are issued birth certificates, it follows that the birth certificates are the authoritative record of all births in the state. The Infant Hearing Screening Tracking Database should, therefore, start with the list of births compiled from the birth certificates. Newborns, however, are often screened for hearing and discharged from the hospital before the birth certificates are issued. In practice, the state EHDI program has to receive the hearing screening data from the hospitals and enter them into the database, and later reconcile these infant records with the birth certificates. Following are some approaches on how to collect the newborn hearing screening results and populate the EHDI tracking database.

**Paper Forms** — Hospitals are required to complete a paper form for each newborn and mail them to the state health department at least once a week. The state health department enters the data into the database by using either manual keying or scanning with optical character recognition (OCR) as in Arkansas.

**Strengths:**

- 1) traditional procedure well understood by hospitals, audiologists and state health department;
- 2) enough space to include required data including risk factors.

**Weaknesses:**

- 1) Potential delays in receiving forms at state health department;
- 2) cost and potential delays of data entry, especially manual keying;
- 3) potential errors in data entered into database (keying or scanning).

**Blood Spot Card** — Blood spot cards are similar to paper forms, but the hearing screening results are reported on the metabolic screening card. The data can be entered into the database either manually or by scanning as in Michigan. The hearing screening data can be entered as part of the metabolic screening database and later exported or linked with the hearing tracking database as in Washington.

**Strengths:**

- 1) expedient way to have newborn hearing results reported to state health department;
- 2) newborn screening database can be easily linked with hearing screening results.

**Weaknesses:**

- 1) hospitals need to coordinate the logistics of metabolic and hearing screening;
- 2) very limited amount of hearing test results can be added to the blood spot cards;
- 3) costs of printing new blood spot cards to include hearing test results;
- 4) potential delay in receiving the blood spot cards at the laboratory;
- 5) need to modify metabolic screening data entry process to accommodate hearing test results;
- 6) need to modify metabolic screening data management and tracking software, or to export hearing test results to a hearing screening tracking system.

**Electronic Birth Certificates (EBC)** — Most states have some form of EBC system that allows hospitals to send birth certificate information to the state vital records department in electronic form. The most common way is mailing computer diskettes or transmitting files using telephone modems. The infant hearing screening results can be added as additional data items or as a separate module within this EBC record, and be transmitted from the hospital to the state vital records department in the usual manner.

In the future, however, the EBC will probably be transformed into a two-way communication channel between the hospital and the state vital records department, and perhaps all programs within the state health department. In this new B probably Internet-based system, much more information can be included and transmitted than just those data items that appear on the printed birth certificate. In examining the Strengths and Weaknesses to this approach, one has to keep in mind the difference between the current system and the “re-engineered” vital records system of the future.

- Strengths:**
- 1) expedient way to have newborn hearing screening results reported to state health department;
  - 2) assurance that all births are entered into the infant hearing screening database;
  - 3) automatic linkage of the infant hearing screening data with data on birth certificates;
  - 4) more accurate information regarding adopted parents and guardians;
  - 5) no inherent limitation on the number of data items;
  - 6) state health department does not have to do data entry;
  - 7) in the future, hospitals may be able to send updated hearing screening information on each child to the state health department through the EBC system.

- Weaknesses:**
- 1) in the current system, there may be a delay of a week or longer before the birth certificate and hearing screening information are received at the state health department;
  - 2) need to modify existing EBC software.

**Databases on Local Personal Computers** — Hospitals and audiologists maintain their own hearing screening tracking databases on personal computers, and they mail data files periodically to the state health department. The state health department has to synchronize the records

with the state EHDI database as in Utah and Colorado. Newer systems may allow electronic transfer of files from hospitals to the state health department using the Internet as in Texas.

- Strengths:**
- 1) detailed hearing screening data can be captured through interface with instruments;
  - 2) hospitals and audiologists can keep track of infants they have screened;
  - 3) hospitals and audiologists can generate follow-up letters to parents if rescreening and follow-up are performed at the same hospital.

- Weaknesses:**
- 1) data from hand-held hearing screening devices often cannot be captured directly into the database;
  - 2) requires more training of staff performing screening;
  - 3) delays in state health department receiving data if data files have to be sent periodically by post office mail;
  - 4) synchronizing databases between hospitals/audiologists and state health department may be cumbersome and error prone.

**Internet-Based On-Line Data Entry** — Hospitals and audiologists can enter data on infant screening results by using a standard web browser as in Virginia.

- Strengths:**
- 1) data are more timely;
  - 2) data are more accurate because of built-in data validation;
  - 3) no restrictions on the amount of data that can be collected;
  - 4) allow hospitals, audiologists and health care providers to query and retrieve information as well as submit data to the state health department;
  - 5) can be the access method to a state-based integrated information system for children prevention services.

- Weaknesses:**
- 1) hospitals, audiologists and health-care providers are required to have computers with Internet access;
  - 2) data only can be entered and viewed on-line.

**Electronic Forms** — This is a new technology that will likely be used more in the future. The electronic form is a file (e.g., Adobe Acrobat PDF forms) that can be electronically sent from the hospitals and audiologists to the state health department, or used in conjunction with a web browser. The electronic forms have built in data validation, and some have password protection and digital signatures. Electronic forms can be automatically “routed” within the state health department. Electronic form data can be automatically extracted and inserted into databases.

- Strengths:**
- 1) easy conversion from paper forms to electronic forms;
  - 2) data are more timely;
  - 3) data are more accurate because of built-in data validation;
  - 4) no restrictions on the amount of data that can be collected;
  - 5) allows for “workflow automation” within the state health department.
  - 6) can be used with a Web browser or sent as email;
  - 7) hospitals, audiologists and health care providers can keep copies of the electronic form for their records;
  - 8) standardized data fields on electronic forms allow hospitals and other hearing tracking databases to automate reporting in the future;
  - 9) can be used to compliment other data reporting methods to communicate with healthcare providers.

- Weaknesses:**
- 1) need adequate safeguards for privacy, confidentiality and security of the electronic forms and data;
  - 2) may take time before state health department information technology departments will accept and adopt this new technology.

## Communicating with parents and health care providers

Parents, healthcare providers, and case managers can be communicated with by:

### *Post Office Mail/Phone Calls*

**Strengths:** 1) traditional approach used by state health departments.

**Weaknesses:** 1) requires staff time;  
2) costs of printing, postage and handling.

### *Electronic Mail (e-mail) With Document Attachments*

**Strengths:** 1) more timely;  
2) low cost;  
3) reminders and reports can be automatically generated and sent electronically.

**Weaknesses:** 1) not all parents or health care providers may have email;  
2) need adequate safeguards for privacy, confidentiality and security of the electronic forms and data.

### *Internet-Based On-Line Systems*

- Strengths:**
- 1) can be used with email notification, e.g., email notice to visit a website for report;
  - 2) allows customized queries and retrieval of other information.

**Weaknesses:** 1) requires on-line access to the Internet.

### *Electronic Forms (used in conjunction with email and web-based on-line systems)*

- Strengths:**
- 1) can be used in conjunction with email and on-line access;
  - 2) parents and health care providers can keep copies of the electronic forms and print them as needed.

**Weaknesses:** 1) need adequate safeguards for privacy, confidentiality and security of the electronic forms and data.

## Data Linkage

Most state health departments receive the following information on each newborn: 1) birth certificate; 2) metabolic screening results; and 3) infant hearing screening results. Some of the data are duplicated in that all reports include demographics of the infant, and locator information for parents and pediatricians. Also, the birth certificate includes information on birth defects, and hearing screening requires the identification of high-risk infants (some birth defects are risk factors for progressive hearing loss).

If the state health department has separate data reporting systems for the birth certificates, metabolic screening, and infant hearing screening, then one approach to using data from one system (e.g., birth certificates) in another (e.g., infant hearing screening) is to try to link all the records in the different systems for each child.

There are well-known problems with linking data records. For example, the names of the child and mother might change, or the date of birth might be missing or incorrect. Databases created using linkages without a unique identifier for each child often have duplicated records for some children or incorrect information on some children because of misidentification.

## Unique Identifier(s) To Link Records and Track Each Child

To track children over time efficiently and minimize errors, state health departments need a way to identify each child uniquely. The birth certificate number is a unique identifier for a child, but that number is not assigned until days or weeks after birth. Also, many states do not wish to use the birth certificate number in health records.

Because the metabolic screening (blood spot) number is assigned to newborns soon after birth, some state health departments have proposed the use of that number as a linking number for infant hearing reporting.

Some states have created a separate unique number for each child to facilitate data linkage. A set of labels with a unique number and bar code are printed on a page. The labels are assigned to each infant at birth. One of those labels is placed on each of the data report forms (metabolic screening, infant hearing screening, and birth certificate) for each patient (or the number is entered on an electronic report form). At the state health department, the data from the different report forms for each child are linked together using this unique identifier.

An alternative to having a single unique identifier for each infant is to have a collection of identifying information on each child. For example, if the state knows the birth certificate number and the blood spot card number for a child, then any data associated with either of these identifiers can be linked together for that child. In other words, a set of linking information can be used instead of a single unique identifier assigned to each child.

The problem is that most state health departments do not have such a set of identifiers for each child in a single database. A simple way to create such a set of identifiers for record linkage and infant tracking is to include these identifiers as part of the electronic birth certificate reporting. The following identifiers are recommended:

- Birth certificate number.
- Blood spot card number.
- Infant’s birth hospital and medical record number.
- Mother’s medical record number.
- Newborn hearing screening test report number (if hearing test results are reported to the state health department independent of the electronic birth certificate or blood spot card).

## Integration for Data Systems: Master Child Index and “Child Profile”

Some states are planning to develop integrated on-line systems that will allow hospitals and healthcare providers to report and receive information in a uniform way that is based on the child, rather than on the type of service provided. An integrated data system for newborns would include all the information shown on birth certificates, metabolic screening and hearing screening reports, and other information on health conditions and prevention services such as birth defects and immunizations. In an integrated system, it would be possible to have an up-to-date summary of health status and services received for each child. Such a summary, or “child profile”, is what healthcare providers and case managers need to care for each child.

The advantages of having an integrated on-line system:

- For hospitals and health-care providers: 1) less burden because of less duplication of data reported and a more uniform method of reporting;

- 2) better healthcare delivery to patients because more accurate and more comprehensive data on each child are reported to the state health department; 3) potential of automating the reporting process by interfaces with the hospital information system.
- For the state health department: 1) more timely data on each child; 2) less burden on data capture, entry and validation; 3) less chance of duplication or wrong information on a child because of mistaken identity; 4) less burden on finding and locating children and families because different programs can share and update information on each child and family, and fewer infants and children will be “lost to follow-up”; e) better healthcare delivery to infants because important information (such as risk factors) that are collected by one program can be used by another for case management.

An alternative to creating a single integrated child health database system is to provide an integrated view of a child based on data retrieved from various databases through dynamic linkage of records as in Utah. For example, each state health department program (e.g., metabolic screening, hearing screening, immunizations) can maintain its own database, but a separate system can be developed to query and retrieve data from these different databases and present the composite information to health care providers.

## Child-Based Integrated Reminder System

Another benefit of an “integrated” data system (using integrated database or dynamic linkage) is that it would be possible to have an integrated reminder system. Instead of receiving numerous reminder messages about different healthcare needs, healthcare professionals and parents could be notified of hearing tests, immunizations, and other health services that the child needs—all in a single message.

## Threats to the Health of the EHDI Tracking and Surveillance System: Addressing Ongoing Challenges

As with the formation of any data system, the EHDI program will face ongoing challenges to the accuracy and completeness of the databases. The ability to successfully address these kinds of challenges will directly affect the usefulness of the system and, ultimately, impact the success of the EHDI program.

### *Receiving Accurate and Timely Reports*

Screening, rescreening, evaluation, and identification of children with hearing loss relies on a variety of professionals making the diagnosis and providing that information to the state or other authorized agency.

Barriers to reporting include:

- Professionals seeing reporting as a burden.
- Problems obtaining informed consent.
- Parental concerns about privacy.
- Reporting staff turnover.

Reporting can be enhanced by:

- Conducting on-site quality assurance visits with providers/staff.
- Holding general educational conferences with providers/staff.
- Conducting on-going, one-on-one training with providers/staff.
- Sending reminder letters.
- Winning over key individuals within agencies and making them advocates.
- Developing advisory groups and champions.

- Providing feedback in the form of annual reports, newsletters, or letters to key administrators.
- Enlisting other health agencies to include the need to report children with hearing loss.
- Designating a state-level coordinator with local ties (e.g., public health nurses).

### *Timeliness of reports*

The EHDI program needs to commit the resources necessary to ensure that the database is processed in a timely manner. Even though programs may get good compliance from all but a few agencies or providers, these noncompliant professionals affect the completeness of the databases, the accuracy of the data, the individual children, and the support others give the program. Potential problems such as computer crashes, staff shortages, and unsuccessful data transfers need to be resolved quickly to ensure optimal functioning of the data system. Once data are obtained, the EHDI program must also be ready to disseminate its findings in a timely manner.

### *Duplicates*

Duplicate reports are the bane of many data systems and the identification of duplicates can be complex and time consuming. Most systems potentially contain duplicates: children can be reported under a variety of names (mother's maiden or paternal), children frequently change names or households, multiple births can complicate identification of a particular child, and errors in reporting key variables such as child name or birth date mask identification of a duplicate. Checking the system internally may identify some potential matches. A system can run multiple sorts on a database and each record can be checked against all other records. Another way to identify duplicates is to match the database against another database thought to contain no duplicates, such as a birth certificate database, and determine if more than one record matches

(however, even birth certificate files can contain duplicate records). If the EHDI program shares the data with other users, they need to know how to report duplicates. Having a unique identifier (or set of identifiers) for each child can significantly reduce—but probably not eliminate—the problem of duplicated records. Other state programs, such as immunization or birth defects registries, may have established procedures for “de-duplication” of records that can be used for EHDI records.

### *Confidentiality*

Because the data system will contain personal identifiers, both parents and providers will always be concerned about confidentiality issues, such as how data are gathered, maintained, shared, and released. Parents who discover that their child’s personal information has been provided to the state for an EHDI program, frequently call the program inquiring by what right the program has the personal information. Often the parents are unhappy about the fact that their child’s personal identifiers are in a state database. Furthermore, they want to know with whom the state will share the information. If the parent has not been previously notified about the system or the program, they could rightly feel that their privacy has already been violated. The ability to assure parents that their child’s personal identifiers are being kept confidential and are being used only for valid purposes is vital to maintaining a healthy EHDI program.

Providers will also have concerns about reporting to the state program, especially if they feel that the state is not vigilant in safeguarding the data. In addition, providers have concerns about federal regulations (such as HIPAA and FERPA)<sup>9</sup>, state policies (historical, real, and perceived), individual liability, and data sharing policies that will continually need to be addressed. Attention to staff education on privacy and confidentiality processes and procedures is necessary on a regular basis, both to provide refresher training to the staff so they do not become complacent, and to educate incoming staff. Staff vigilance is important because if there is a

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<sup>9</sup> See Chapter 6 for in depth discussion of these and other federal regulations and their impact on EHDI programs.

perception that a breach of confidentiality is possible, support for the EHDI program will be compromised. Providers will not want to report to the state; moreover, parents will not want to participate and they could influence lawmakers to modify the program's data collection capabilities.

### *Completeness and Accuracy*

The usefulness of the EHDI data system is directly affected by the information contained in the databases. If the data are incomplete or inaccurate, then the information is less useful. Ideally, there should be an estimate of how complete the databases are (i.e., the coverage rate). Stakeholders, other professionals and the public may be interested in attacking results from the data system unless the EHDI program can show that the data are complete and accurate.

### *Obtaining Necessary Information*

Related to the completeness and accuracy challenge is the ability of the EHDI program to actually obtain the desired data. Ideally, the EHDI surveillance and tracking system will contain a variety of outcome measures, and will be used for long-term tracking. Parental informed consent will probably be required in order to have access to both education records and parent tracking information. Even with consent, EHDI program staff will need to establish on-going agreements with other agencies to access this type of information.

### *Out-of-State Events*

There are several out of state events that need to be addressed by the EHDI program. First, since all states have resident births which occur out of state, there will need to be a process in place to ensure these children are offered screening. Depending upon each state's vital record policies, state EHDI programs might or might not have access to birth certificates for those resident births that occur out of state. Each state EHDI program

should check with its registrars and Vital Records Exchange Program policy, as established by the National Association for Public Health Statistics and Information Systems (NAPHSIS). The Vital Records Exchange Program specifies how resident births occurring in other states can be used, depending on the actual state of birth.

Second, children with hearing loss who were birth residents of another state will move into the state, and will need services. If these children become part of the state surveillance system, they will need to be identified so the state can exclude them from selected statistical calculations (such as birth prevalence rates).

The third concern is for children with hearing loss who move out of state. Every state EHDI program will need to decide if and how to track these children, especially with regard to communication and long-term outcomes. Since tracking children is an on-going part of newborn metabolic screening in each state, the EHDI program can use that procedure as a model for follow-up of children identified to have permanent hearing loss.

## References

1. CDC. Updated guidelines for evaluating surveillance systems: recommendations from the guidelines working group. *MMWR* 2001;50(no. RR-13).
2. CDC. Guidelines for evaluating surveillance systems. *MMWR* 1988;37(no. S-5).

## EHDI Tracking System and Surveillance Checklist

Early hearing detection and intervention is one of many prevention services programs that the state health department provides. Tracking systems for children should consider these functional requirements of an integrated information system for children prevention services:

### *Database*

- Screening/evaluation database and registry database—single integrated database vs. separate linked databases

### *Core Data Items*

- Data items required to track health status, health services provided, and medical/intervention needs of each child. (See Appendix 3 for Core Data Items for EHDI)

### *Electronic Reporting to State Health Department*

- Enable birthing hospitals and health-care providers (hospitals, clinics, pediatricians, audiologists, intervention specialists) to submit data about newborns to state health department using Web browser and/or electronic forms: birth certificate; infant hearing screening; metabolic screening; birth defects; immunizations; and other conditions

### *Unique Child Identifier(s)*

- Create a unique identifier or use a set of identifiers for all infants and children

### *Master Child Index*

- Create an integrated master index of all children living in the state and current information about their family and health-care providers to facilitate follow-up

## EHDI Website Checklist (*continued*)

### *Child Profile*

- Create an integrated “child profile” that summarizes relevant information about the child’s health status, family and health-care provider information, preventive health services recommended, and due dates for these services.

### *Electronic Data Access by Healthcare Providers*

- The child profile should be accessible by authorized health care providers and case managers.

### *Integrated Reminder System*

- Develop a single integrated reminder system for automatic notifications to health-care providers and case managers about services needed for each child, and automatic reminders to parents to bring their children in for health services.

### *Data Quality*

- Assure that data in the database are complete, accurate, up-to-date and not duplicated for any child.

### *Timely Reports*

- Produce statistical reports on a regular basis with timely information.

### *Privacy and Confidentiality of Data*

- Potential issues: 1) whether parental consent is required for infants to be included in the tracking system; and 2) need for agreements among state agencies to share information.

### *Out-of-State Events*

- Develop plans on how to follow-up out-of-state births and families who move out of state.

## CHAPTER 8

### Tracking: Screening Through Evaluation

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One of the biggest challenges that each EHDI program faces is developing a database system that will allow the state to know the hearing status of every baby born in the state. This tracking system must include every baby, the follow-up status of all babies needing further services, and designate the EHDI status of each baby. The system should be user friendly and readily accessible to those authorized to use the system.

For the state EHDI database to function effectively, individual hospitals, clinics, referral facilities, and other services providers must furnish uniform data to the lead or coordinating agency. The data and information received by the coordinating agency, which is often the state department of health, can then be used to improve the services provided to infants and their families, assess the quality of various components of the EHDI system, and promote program measurement and accountability. Therefore, states should work to develop integrated systems of services and care that allow states to provide feedback to hospitals regarding how they compare with other hospitals in the state, and permit the state to determine the number of infants needing and receiving services within a specific time period.

### Communicating With EHDI Stakeholders

Clear communication among all of the stakeholders within the state EHDI system is vital to the ultimate success of the program. Each professional and family member involved should understand his or her roles and responsibilities within the state EHDI program. Many states have found it useful to develop written guidelines outlining specific protocols regarding not only data input, but also procedural issues, sequencing of events, and interpersonal communications that provide critical information to the stakeholders at each level within the system. Programs

might find it beneficial to create an information flow chart outlining answers to the following questions.

- Who will provide information and to whom will the information be provided?
- Who will provide information to families and primary care providers (PCPs) about screening results?
- Who is responsible for reporting the status of each infant at the time of hospital discharge to the state EHDI program?
- Who are the EHDI stakeholders at each stage in the EHDI system?
- What information will be provided?
- What follow-up services are available to families of infants who are referred?
- What are the developmental milestones for hearing, speech and language?
- What places a child at risk for developing a hearing loss later in life? (See end of chapter for listing of risk factors.)
- How will the information be conveyed?
- How will information be shared—in writing, person-to-person, electronically, in a different language?
- When will the information be conveyed?
- When will parents be informed of screening results?
- When will information regarding follow-up services be provided?
- When will information be provided to referral sources and to the state EHDI program?

The EHDI system should provide a seamless stream of services, beginning with the hearing screening before hospital discharge, through the repeat hearing screening (rescreen), hearing evaluation(s), and early

intervention services. Clear communication among all stakeholders is vital to the effective use of the EHDI system, and in reducing loss to follow-up. Thus, it is necessary to ensure that all stakeholders are educated regarding their roles and responsibilities within the EHDI system.

## Babies Who Need Follow-Up Services

The previous chapter discussed the need for ensuring that all babies are entered into the EHDI system. Many EHDI programs have found it useful to enter additional information for babies who do not pass the hearing screening before being discharged from the hospital to allow for easier follow-up. The follow-up protocols differ among states, and even within states. Some programs will ask parents to return with their infants for a repeated hearing screening (a rescreen) of their baby's hearing before proceeding to a more complete diagnostic assessment, while some programs will refer families directly to an audiologist to complete the diagnostic evaluation. There are advantages and disadvantages to each approach, particularly with regard to: 1) the cost of the services being provided; and 2) the amount of time required both to complete the screening or testing, and to schedule further appointments for additional follow-up services. Programs should develop their referral protocols based on their program demographics, availability of personnel within the hospital to complete follow-up testing, availability of referral sources within the community, and other program-specific information related to the EHDI system. There is no single "best" protocol for all programs to adopt, but instead each program needs to develop the protocol that allows it to best fulfill its role in the overall early identification/early intervention system.

Regardless of the follow-up protocol, each program component should provide a clear and well-developed mechanism for reporting back to the state's centralized EHDI system. As babies are discharged from the hospital, the complexity of follow-up increases dramatically as the once "captive audience" is lost. The EHDI program is then dependent on each and every follow-up provider and facility to report back to the system to update each baby's EHDI status.

## List of Referral Sources for Pediatric Services

One activity that many states have found useful is the completion of a survey of referral sources (audiologists, ear, nose, and throat (ENT) doctors, and related healthcare providers) to determine which professionals have the experience, expertise, instrumentation needed to complete evaluations of infants in the EHDI system. The EHDI program involves a two-way flow of information: from the state to the providers and from the providers to the state. It is often the case that not all of the information collected and received at one level is shared with everyone else in the EHDI system—only that information which is deemed pertinent. State EHDI programs need to know who their referral sources are, where referral sources are located, how to contact their referral sources, and what services are (and are not) available for each referral source. Referral sources need to know which patients are in the EHDI system; what information needs to be forwarded to the state; to whom information is to be forwarded; and the pertinent rules, regulations, and policies that apply regarding release of information and confidentiality. States should involve referral sources in the overall EHDI system, and gain their feedback regarding key components of how well the EHDI system works. For instance, although it ideally might seem advantageous to the state to implement a web-based reporting mechanism, if practitioners do not have access to the Internet at their offices, complications can arise, and alternatives must then be sought. A list of contact people from each state is found on the CDC EHDI website at [http://www.cdc.gov/ncbddd/ehdi/documents/stateHL\\_contacts.pdf](http://www.cdc.gov/ncbddd/ehdi/documents/stateHL_contacts.pdf)

## Reducing Initial Refer Rate

The purpose of the EHDI program is to identify infants with hearing loss. The pressures of reducing the initial referral rate should not be allowed to detrimentally affect the program's ability to identify children with hearing loss and ensure that necessary and timely services are provided. Although it might be tempting for a program to increase the stimulus level being used to pass more babies, doing so risks passing a baby a with milder

degree of hearing loss. The following list includes some of the better documented methods for reducing the initial refer rate.

- Hearing screenings should be scheduled in a quiet area during nursery “down” times.
- A baby should be allowed several attempts to pass the screening before hospital discharge.
- The manufacturer’s recommendations should be followed for calibrating and maintaining the screening equipment.
- Back up screening equipment and supplies should be readily available.
- The statistics for each screener should be monitored, and screening personnel should be retrained on a routine basis.

## Provide Access to EHDI Services for Babies Not Born in Hospitals

Although the overwhelming majority of babies are born in hospitals, each state can expect to have a small number of out-of-hospital births. The EHDI program should develop a mechanism for ensuring that these babies have access to hearing screening services. Similarly, “border babies”—that is both babies who are born out of state or babies from other states who are born in state—should be accounted for within the overall EHDI system. Many states are working diligently to develop working relationships with their border states to reduce loss to follow-up. Additionally, states have developed educational programs for midwives through the American College of Nurse-Midwives, the Midwives Alliance of North America, or similar state associations. Other states focus attention on the professionals working in alternative birthing centers.

## Minimizing Loss to Follow-Up

A well-designed and implemented tracking program can assist the state in identifying each individual infant referred and reducing the number of infants who fail to return for recommended follow-up services. There are many reasons that a family does not return for follow-up services, including (but not limited to) a lack of communication with the family, less than enthusiastic support for the EHDI program from the primary care provider (PCP), and the inability of the EHDI program to contact the family for scheduling services. Suggestions for reducing the number of babies lost to follow-up include:

- Ensuring that families know what they are to do next. Whenever possible, families should be provided with the appropriate information face-to-face and in writing.
- Scheduling the next appointment before the family leaves the hospital.
- Identifying the PCP (or Physician of Record) before the baby leaves the hospital (not simply the name on the birth certificate).
- Keeping the time between scheduled appointments to a minimum.
- Providing families with a name and the phone number of someone to contact if they have questions about the EHDI program, the hearing screening, or the services for which they are being referred.
- Educating healthcare providers in the community of the importance of families returning for follow-up services, giving both health care providers and families information regarding who to contact to answer questions, and referring families for further services if they suspect hearing might be a problem.
- Using a tracking program that generates tickler files indicating which babies are overdue for follow-up services.

- Addressing cultural and linguistic aspects of infants' families to meet the needs of a diverse population. When the demographics of the population being served by the state EHDI program warrant, have materials available in languages other than English.
- Ensuring that a mechanism is in place for identifying which families need materials in which languages.
- Asking the family for the phone number or e-mail address of a friend, neighbor, or relative not living in the household, who can contact the family when the information provided at hospital discharge is no longer valid.
- Documenting that the referral facilities providing follow-up services to the infants and families referred from the newborn hearing screening program have the necessary instrumentation, training, and expertise to provide the appropriate services.
- Coordinating services with other screening or child healthcare programs.

## Risk Indicators for Late Onset/Progressive Hearing Loss Checklist\*

The Joint Committee on Infant Hearing (JCIH) recommends the following indicators for use with neonates or infants (29 days through 2 years). These indicators place an infant at risk for progressive or delayed-onset sensorineural hearing loss and/or conductive hearing loss. Any infant with these risk indicators for progressive or delayed-onset hearing loss who has passed the birth screen should, nonetheless, receive audiologic monitoring every 6 months until age 3 years. These indicators are:

- Parental or caregiver concern regarding hearing, speech, language, and or developmental delay.
- Family history of permanent childhood hearing loss.
- Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or Eustachian tube dysfunction.
- Postnatal infections associated with sensorineural hearing loss including bacterial meningitis.
- In-utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis.
- Neonatal indicators-specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation (ECMO).

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\* Source: Joint Committee on Infant Hearing Year 2000 Position Statement: Principles and guidelines for early hearing detection and intervention programs. American Journal of Audiology, 9, 9-29.

## Risk Indicators for Late Onset/Progressive Hearing Loss Checklist\* (continued)

- Syndromes associated with progressive hearing loss, such as neurofibromatosis, osteopetrosis, and Usher syndrome.
- Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome.
- Head trauma.
- Recurrent or persistent otitis media with effusion for at least 3 months.

Because some important indicators, such as family history of hearing loss, may not be determined during the course of UNHS programs, the presence of all late-onset risk indicators should be determined in the medical home during early well-baby visits. Those infants with significant late-onset risk factors should be carefully monitored for normal communication developmental milestones during routine medical care.

## Tracking: Screening Through Evaluation Checklist

### *Communicating With Stakeholder*

Programs should determine:

- Who will provide information
- To whom it will be provided
- By what means it will be provided
- When information will be provided

### *Follow-up Protocols*

Referral protocols should be based on:

- Demographics
- Availability of personnel
- Availability of referral sources in the community
- Program-specific information

### *Referral Sources*

Programs need to know:

- Who referral sources are
- Where they are located
- How to contact them
- What services are/not available

Referral sources need to know:

- Which patients are in the EHDI system
- What information needs to be reported
- Where to forward the information
- Rules and regulations regarding confidentiality

## Tracking: Screening Through Evaluation Checklist (continued)

### *Other Program Challenges*

Programs should develop strategies to:

- Reduce initial refer rates without jeopardizing milder cases
- Gain access to babies not born in hospitals
- Minimize loss to follow-up



## CHAPTER 9

# Registry of Children with Hearing Loss — Long-Term Tracking

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Once states begin to gather data on children who do not pass hearing screening and track them through diagnosis, the next step will be to create a registry of children who have diagnosed hearing loss. In its simplest form, a registry is a confidential listing, usually in electronic form, of individuals who share a characteristic. Once established, and depending on each state's statutes, resources, and initiatives, a registry of children with hearing loss can be used to:

- Determine the number and distribution of the population affected by hearing loss.
- Provide baseline information for research and investigations.
- Provide data for health planning, delivery and evaluation.
- Provide data for long-term outcomes and service evaluation.
- Detect changes in health practices.
- Educate the public and concerned professionals about the occurrence of hearing loss.
- Identify individuals who would benefit from early intervention or the provision of other medical/social/emotional services<sup>10, 11</sup>.

Registries can be used as a population data source and/or as a client management information system. As children with hearing loss are identified and entered into a registry, data will be available to estimate

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<sup>10</sup> Michele C. Lynberg, Larry D. Edmonds, "State Use of Birth Defects Surveillance", Data to Action, U.S. Department of Health and Human Services, 1994.

<sup>11</sup> Steven M. Teutsch, R. Elliot Churchill, eds., Principles and Practice of Public Health Surveillance, Second Edition, Oxford University Press, 2000

both the prevalence and incidence of hearing loss, and to describe the population of affected children. Those data also can then be used for a broader range of program activities, such as planning, evaluation, increasing resource allocation, and advocating for children with hearing loss. Once a registry is formed, the children and their families can be invited to participate in research studies, which might identify causes of hearing loss or prevention strategies. Finally, a registry can be an efficient and cost-effective way to identify children and families who might benefit from a wide range of interventions, including entitled services.

## Planning the Registry

A first step in designing and establishing a registry is to determine what other registries exist in the state, and the format of those registries. In some states, the registry of children with hearing loss may become a component of an existing, integrated public health reporting system, while for other states, it will be a stand alone database, that can be linked to other databases. In either case, the EHDI program should review what currently exists, determine what kind of support the regulatory department can provide, and design the registry that provides the most flexibility within budget and personnel limitations. In designing the registry, the EHDI program should answer several questions.

### *Purpose*

Why create a registry? In the end, what questions need to be answered, or why is the information being collected? Is there a single purpose or are there multiple purposes for collecting the data? If there are multiple purposes, are they complementary or do they lead to conflicting data structures? Will the registry be used to contact families?

## *Legal Authority*

Is there a specific legal requirement for the registry? If not, can data be collected as part of the general functions of a regulatory agency (such as the department of health)? Is informed consent needed? Do the legal requirements benefit or hinder creation and use of the registry? Do the legal requirements address data items, data use, confidentiality, or other critical items that impact the structure/content of the registry? If there is no legal authority, who will be included in the registry and what will be done to maximize complete reporting?

## *Confidentiality*

How will the confidentiality of paper and electronic reports and the registry be maintained? Who will determine and be responsible for such items as passwords, encryption, and data transfer? Who will have access to the reports listing the names of the individuals in the registry?

## *Stakeholders*

Who are the stakeholders? Will the registry meet the needs of all the stakeholders? Are the stakeholders supportive of the creation and use of the registry? How will the needs of all the stakeholders be assured?

## **Gathering the Data**

Once the conceptual framework of the registry is established, the next step will be to design the database. The database will need to work within any existing requirements of the regulatory department, be able to be modified, and may need to be flexible to accept data in different formats. If the database will be used to generate letters to families, or notifications to service providers, it will need to support the mechanics of generating those kinds of documents. Key questions to consider follow.

### *Manager*

Who will be responsible for data collection, data integrity, confidentiality, access, use, and evaluation? Who will have ultimate authority for the registry?

### *Hardware/Software Issues*

What database structure or program will be needed to maintain the data in the most optimal manner? What hardware and software components will be needed to ensure the confidentiality of the data? What system(s) will be used to build the registry? What hardware is needed to support the database and ensure cost-effective processing? How can the database be modified to meet future needs? As changes are made to the data, is there a need to keep track of the changes and who made them? What back-up systems will be needed to ensure appropriate data maintenance?

### *Reporting Agencies/Databases*

Who will be providing data to the registry? Are the mechanisms in place to accept data from multiple reporters? Are duplicate reports possible? How can unique cases be identified?

### *Data Reporting*

What data items will be collected? Will the data be on paper, be transmitted electronically, come directly through web-based reports, be available from other existing databases, or be available through some other means? How will reports be updated? If more than one report is received, how will conflicting data elements be resolved?

### *Data Transfer*

Will the data be on a stand-alone system, be linked to other relevant datasets, be integrated with other datasets, and/or be sent to other organizations? If the data are transmitted electronically, what steps will be taken to ensure the confidentiality of the transfer?

### *Data Processing*

Once data are received, they will need to be processed. This might involve manually entering the data or merging electronic reports into the main database. Some data might need to be coded, and some data might represent “updates” to existing records. The data will need to be cleaned for both valid range checks and logical consistencies. As changes are made to the data, programs might want to ensure that they can track each change using a transaction record or other tool. Finally, the database needs to be checked for duplicate information.

### *Data Collection/Coding/Entry/Cleaning*

Who will collect the data? Who will code the data and how? Who will enter the data? Will data need to be merged with that from other sources? How timely will data processing be? How will the data be cleaned (valid ranges, data consistency, etc.)? How frequently will the data be cleaned?

### *Nonduplicated Records/Unique Identifiers*

What steps will be taken to ensure there are no duplicate records in the database? How will unique cases be identified? Is there a need to identify siblings or other related family members? Can birth certificates or another independent source be used to identify potential duplicates?

## Data Quality and Usage

Once the data have been collected and cleaned, they can then be analyzed and distributed. The EHDI program should ensure that data analysis meets the needs of all stakeholders. In disseminating the data, care needs to be taken to maintain the confidentiality of the children in the registry and their families. This might include data suppression, as well as employing other data manipulations that protect the privacy of individuals. Additionally, the EHDI program should identify other sources or procedures that ensure that no child with hearing loss has been missed. This will mean that the EHDI program will have to identify independent procedures that can be used to assess the completeness and accuracy of the data in the registry of children with hearing loss. Finally, the data also will provide the EHDI program the means to conduct program evaluation, a critical component of any public health activity.

### *Use*

How will the resulting data be used? Will the collected data be sufficient to accomplish the purpose(s)? Are other data needed to complete the picture?

### *Analysis/Interpretation*

How will the data be analyzed? What standard reports are needed?

### *Data Dissemination*

How will the results of the data analysis be distributed to the key stakeholders? Will the data only be released in tabular form, or will microdata sets be available? How will data be suppressed to ensure the privacy of individual children and families? Are there other publicly available datasets, which if matched to an EHDI microdata file, may be likely to identify an individual child?

## *Quality Assurance*

What quality assurance procedures will be implemented and how will the completeness of the database be assessed? What independent data sources can be used for quality assurance? Can source records be reviewed to ensure accuracy of reported information? What general steps will be taken to ensure that the database is complete and accurate?

## *Evaluation*

Using the available data, are the components of the EHDI system meeting the goals and objectives of the program and stakeholders?

## *Implementation*

By following the procedures outlined in Chapter 7, and answering the preceding questions, states will be able to plan, implement, and maintain a registry of children with hearing loss. Minimally, a registry of children with hearing loss should provide both descriptive and outcome data. Data on the results of screening, the audiologic evaluation, the medical diagnosis, interventions offered and received, as well as measures or assessments of language comprehension and expression are needed. To the degree possible, the registry should contain data that can be used for tracking. To maximize the use of the data in the registry, the registry needs to be accurate, comprehensive, and current. The data in the registry should be disseminated, and can be used for program description, planning, and evaluation.

## *Housing the System*

Each state will need to determine where best to locate the EHDI tracking and surveillance system. For some states, the EHDI system might be absorbed into existing newborn screening programs or other programs for

children with special health-care needs. Other states might view EHDI as part of the maternal child health program, as part of vital records, or as part of overall public health surveillance. Some states have established the EHDI system as a stand-alone program, while others have added it as a component of a fully integrated data warehouse. How a state chooses to implement its EHDI program will affect key components in the EHDI system.

### *Using Existing Databases*

Building the EHDI system on data that are currently available, and readily accessible, is both efficient and cost-effective. Matching existing databases can:

- Reduce the burden on reporting agencies and program staff.
- Reduce the burden on families.
- Reduce the amount of time spent obtaining missing data.
- Provide data comparability.
- Minimize data entry errors.
- Improve case finding.
- Improve quality assurance activities.
- Provide information to use in evaluating the system.
- Provide more up-to-date information for tracking each child.
- Provide access to more current information on address, insurance, or other variables of interest.
- Identify and build stronger collaborations among programs.
- Lead to investigation of wider research questions.
- Identify additional partnerships.

## *Integrated Data Systems*

Even with careful planning, stand-alone data systems usually duplicate efforts across and within programs. Establishing a systemwide integrated database allows data on an individual to be centrally collected and used by a wide range of programs. Once established, these systems can provide timely and consolidated information, and serve as a virtual medical record, consisting of all relevant information on every child. Such a comprehensive record would not only benefit service provision by the state, but also, by the child's medical home provider(s). Since data are standardized, with core variables having the same definitions, comparable analysis across populations is possible. To maximize efficiency, agencies transmit information electronically, using either a modem or Web-based system. Electronic reports are timelier, reduce the burden both on reporting and receiving agencies, and maximize the information available to any one program.

A fully integrated system takes time and an on-going financial and personnel commitment to create and maintain. A lead agency and program need to be designated, that will work collaboratively with all other internal and external partners. States that do not have the infrastructure or support to create a new, comprehensive integrated data system might be able to improve data collection by building upon an existing program.

States do not have to develop integrated systems on their own. Over the past several years, there have been a number of vendors who have developed integrated system platforms that address confidentiality and security, data transfer, data access, data analysis, and data reports.

Whatever data system is produced, it needs to be flexible enough to address the changing needs of the program.

## *Determining Data Access*

EHDI programs will have to decide who should have access to the registry. Within each state, there are probably a number of stakeholders who would benefit from access to the registry, such as physicians, audiologists, Part C providers, and case managers. These individuals work closely with children with hearing loss, and might benefit from knowing if a specific child is registered, and if so, what information is in the registry. Depending upon state law and rules, or on the authority of the regulatory department, EHDI programs may transmit information from the registry to providers. Furthermore, the state EHDI program would need to determine how much information to provide to these other stakeholders. For some, access to the entire database may be needed, while for others, they would need access to either selected records (such as their patients) or selected variables. Additionally, it would be essential to have separate confidentiality policies with all parties who have access to the data. These policies should address such basic issues such as who would have access, for what specific purposes could the data be used, how is the data to be maintained, and under what circumstances could the data be further released. Some programs may be able to set up direct access to the registry via either a modem or internet link, using a preapproved confidential access number (medical license number, provider social security number). Some programs may not be able to directly share any of the information in the registry other than to the parent or guardian of the child.

## Registry Checklist

### *Planning*

- What is the purpose of the registry?
- Is there a specific legal authority/requirement for the registry? If not, how will the registry be populated? What will be done to maximize reporting?
- How will confidentiality be maintained?
- Who will have access to data?
- Who are the stakeholders and will the registry meet their needs?
- Can the registry be matched or integrated with any other databases?

### *Gathering Data*

- Who has responsibility for data collection, integrity, confidentiality, access, use and evaluation?
- Who has the ultimate authority over the database?
- What hardware and software will be needed to run the system?
- What back-up systems are needed?
- What data will be collected, how and by whom?
- How will the data be collected: paper, electronic, other reporting mediums?
- Will the registry be matched to other databases to verify or to merge information?

## Tracking: Screening Through Evaluation Checklist (continued)

### *Data Processing*

- Who will collect, code, enter, merge, and clean the data?
- How will these be accomplished?
- How will timeliness be assured?
- How will duplicates be identified and deleted?

### *Data Quality and Usage*

- How will data be used?
- How will data be analyzed?
- In what format will the data be released?
- What standard reports are needed?
- How will quality and completeness of data be assured?
- How will the confidentiality and privacy of individuals be protected in released data?
- What quality assurance techniques can be used to ensure the accuracy and completeness of the registry?
- Are the components of the EHDI system meeting the needs of the stakeholders and the EHDI program?

## Tracking: Screening Through Evaluation Checklist (continued)

### *Implementation*

- Where will EHDI tracking and surveillance system be housed?
- Will the database be an integrated or stand-alone system?
- Will the state develop its own system, or will a vendor be used?

### *Data Access*

- Who will have access to data?
- What laws govern data access?



## CHAPTER 10

# Coordination of EHDI with Other State Health and Educational Programs

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The EHDI program is one unit within state government that addresses the status of children.

Each state EHDI program needs to determine which state programs address common populations or concerns, as collaboration will increase opportunities for success. Following are some activities that are typically undertaken by states, which can provide opportunities for coordination and collaboration. This list is not exhaustive, but is intended to provide some examples of how internal collaborations can benefit the EHDI program.

### Newborn, Infant and Child Health Programs

Each state has numerous programs that deal with the health of infants and children, such as Maternal and Child Health, Children with Special Health Care Needs, Dried Blood Spot Screening, Birth Defects, Healthy Start, and Women, Infants and Children (WIC). Also, states often have a school health program, which involves school or public health nurses. Since these programs usually have been in existence longer than the EHDI program, they may be a strong resource, and may have established complementary services to those needed by the EHDI program. These programs can provide opportunities to identify new partners, develop collaborative educational materials, and work to ensure comprehensive quality assurance initiatives, as well as to address other programmatic areas.

## Genetics

Genetics programs may be separate, or may have activities incorporated into Maternal and Child Health or other programs. EHDI programs should coordinate with the ongoing genetics activities in their states to ensure that issues affecting children with hearing loss and families with children who have hearing loss are included in the state agenda. It is known that genetic factors play a role in the etiology of about 50% of hearing loss, and genetic evaluations are recommended for children with hearing loss. In 2002, the American College of Medical Genetics published Genetics Evaluation Guidelines for the Etiologic Diagnosis of Congenital Hearing Loss (Genetics in Medicine, Vol. 4, May/June 2002). Both the genetics and the EHDI programs should be aware of these guidelines and promote appropriate recommendations. If states develop genetics guidelines for the clinical evaluation of newborns and children, the concerns of families with children with hearing loss should be included.

## Licensing (Physicians, Audiologists, Nurse Practitioners, Midwives, Hospitals)

States license healthcare facilities and health professionals providing services in their states. Knowing the licensing requirements of the facilities and healthcare professionals can provide leverage to ensure compliance with state laws, and adherence to the “1-3-6” plan. EHDI programs may be able to work with Boards of Medical Examiners and professional organizations to educate and advocate for compliance with newborn hearing screening and evaluation activities. Any announcements that are sent by the state, or professional organizations discussing mandated reporting by healthcare professionals should include appropriate reference to hearing requirements. When hospitals are licensed, standards for newborns may be specifically addressed, and when appropriate, should include the requirements of newborn hearing screening. Nurse practitioners and midwives may be particularly important to outreach to families whose babies are not born in hospitals.

## Education

All states provide early intervention services to the birth-to-3 population, under the Individuals with Disabilities Education Act, Part C (Infants and Toddlers with Disabilities). However, states vary in how they determine eligibility for services. Some states serve the at-risk population, some serve only those children with significant hearing loss, while others serve all children with any hearing loss (see <http://www.nectac.org> for a more detailed description of Part C, including a list of state coordinators and the level of developmental delay required for eligibility). Children with hearing loss are often not specifically mentioned within the existing Part C guidelines, and EHDI programs need to collaborate with the Part C to ensure children with hearing loss are appropriately included within the eligibility criteria. Additionally, states might have one or more state schools for the deaf. The EHDI program will be identifying children potentially eligible for services or who may need other types of intervention, and should be a strong partner with Part C and Part B special education programs to ensure age-appropriate services are available. Additionally, these programs will have intervention and outcome information useful for EHDI program evaluation.

## Deaf or Hard of Hearing Programs and Programs for Individuals with Disabilities

Programs serving the deaf or hard of hearing and populations with disabilities are often located within the health or human service departments. Even if these programs do not serve children, the EHDI program should partner with them to identify stakeholders, parent support, long-term concerns, and advocates. These programs may have strong outreach efforts to their constituents, that may be useful for newly established EHDI programs. As part of the outreach efforts, surveys/focus groups/meetings may also be held. The EHDI program may be able to use such outreach mechanisms to promote the goals and objectives of the program.

## Surveillance Programs

States maintain a variety of surveillance systems, such as those for birth defects, immunization, lead, cancer, child abuse, HIV/AIDS, and metabolic screening. These programs have addressed many of the issues facing EHDI programs, such as database hardware and software, reporting, service provision, data linkages, and data dissemination. As states begin to implement or expand their EHDI activities, it will be useful to solicit information and advice from these other programs, as well as seek opportunities for collaboration. Collaboration will provide opportunities for data linkage and integration as well as research. Data sharing can often produce cost and time benefits, create seamless systems, improve productivity, and reduce duplication of efforts. These programs may also have model reports, have experience in statistical analysis and disseminating data to the public, and use Geographic Information Systems (GIS) mapping techniques and other technical experience that would be helpful to the EHDI program.

## Vital Records/Health Statistics

The state's vital records or health statistics program, provides the most accurate source of births and deaths in the state. Coordinating with vital records can provide opportunities to improve the collection of vital records and improve response to specific program needs.

## State Epidemiologist

All states have a designated epidemiologist and may have a chronic disease epidemiologist or Maternal and Child Health epidemiologist, who can provide information to, and collaborate with, the EHDI program. Keeping the state epidemiologist informed of key EHDI program activities may provide another avenue to promote EHDI activities in other venues across the state and nationally. For a list of state and chronic disease epidemiologists, see <http://www.cste.org>.

## Environmental Health/Epidemiology

States maintain a number of environmental health databases, such as those for water quality, Superfund sites, and air quality. These databases may be used to investigate pregnancy outcomes, and should be aware of the EHDI program, so it can be included in appropriate investigations.

### Pregnancy Risk Assessment Monitoring System, Behavioral Risk Factor Surveillance System and Other Department Surveys

As part of ongoing needs assessments or program evaluation, state agencies may conduct or participate in surveys of residents. One of the better known surveys is the Pregnancy Risk Assessment Monitoring System (PRAMS), which collects state-specific, population-based data on maternal attitudes and experiences prior to, during, and immediately following pregnancy ([http://www.cdc.gov/nccdphp/drh/srv\\_prams.htm](http://www.cdc.gov/nccdphp/drh/srv_prams.htm)). PRAMS data have been used by some states to determine the rate of infant hearing screening, and to determine maternal knowledge of the hearing screening program. Another study is the Behavioral Risk Factor Surveillance System (BRFSS), a national survey that states can augment with state-specific questions (<http://www.cdc.gov/brfss/index.htm>). The EHDI program should investigate whether this survey would be useful for program evaluation or other program priorities. States may also conduct other health-related surveys that can be used by the EHDI program. If there are none, the EHDI program may want to partner with other agencies to share the costs of initiating a survey or other data collection tool.

## **Indian Health Services, Tribal Councils, and Military Bases**

States with American Indian, Native Alaskan, or military-base births will have opportunities to work with local/state/federal agencies serving these groups. The EHDI program will want to collaborate with existing health initiatives serving these communities or facilities to ensure that, whenever appropriate, newborn hearing screening and evaluation activities are included in existing health practices. Also, these groups may have special intervention needs, requiring innovative solutions.

## **Medicaid, Child Health Insurance Programs (CHIP), and Other Insurance Providers**

The EHDI process consists of multiple health and medical procedures that need to be reimbursed. The question of “who will pay” is important to families and the providers of the services. Some states have legislatively addressed reimbursement for some or all components of the system, while other states leave it up to the providers. Through education and advocacy, the EHDI program can inform key decision makers of the issues facing families in the acquisition of appropriate services.

## Coordination Checklist

EHDI programs may want to collaborate with the following types of programs/agencies:

### *Newborn, infant and child health programs*

- Maternal and Child Health
- Metabolic Screening
- Birth Defects
- Healthy Start
- WIC

### *Children with Special Healthcare Needs*

- School and/or public health nurses

### *Genetics programs*

### *Licensing programs*

- Physicians
- Audiologists
- Nurse practitioners
- Midwives
- Hospitals

### *Education programs*

- IDEA, Part C
- State school for the deaf
- Deaf or hard of hearing programs and programs for individuals with disabilities

## Coordination Checklist (continued)

### *Surveillance programs*

- Birth Defects
- Immunization
- Lead
- Cancer
- Child Abuse
- AIDS/HIV
- Metabolic Screening

### *Vital records/health statistics programs*

### *State epidemiology programs*

### *Environmental health programs*

### *PRAMS, BRFSS and other departmental surveys*

### *Indian Health Services and Tribal Councils*

### *Military Bases*

### *Medicaid, Child Health Insurance Programs and other insurance providers*

## CHAPTER 11

# Coordination of Health Care Services and The Medical Home

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Children with special needs often receive a battery of services and interventions involving medical, developmental, educational, and social professionals. The Maternal and Child Health Bureau and the American Academy of Pediatrics have championed the concept of the medical home, in which the primary healthcare provider and family work together to ensure that these services are appropriate, available, and integrated<sup>1, 2</sup>. Health care is provided in a variety of venues, including: primary care providers' offices, specialists' offices, outpatient clinics, health department clinics, schools, etc. A medical home can be located in any of these settings.

### The Medical Home Concept

The medical home is centered on the activity of case management, now called care coordination<sup>3</sup>. Care coordination includes the family, as well as the provider. Family members are experts on their child's needs, skills, and strengths; therefore, including them in the development and implementation of a treatment plan increases patient satisfaction, enhances integration of services, and decreases the duplication of efforts with its associated costs<sup>4, 5</sup>. The primary healthcare provider is also a critical team member, whose participation helps reduce incomplete, expensive, fragmented care<sup>4-7</sup>. The provider can take the lead role in the care coordination team if the child's needs are complex or the family is not equipped to play this role, or both. But ideally, the provider should work to empower family members and maximize their role in the care coordination activities.

*Healthy People 2010 Act* goals 16 through 22 aim to increase the accessibility of medical homes for children with special health care needs. It specifies that:

Care for children with special healthcare needs should be provided and coordinated through a “medical home” that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent, and linguistically appropriate. Physicians and parents share the responsibility for ensuring that children and their families have access to all of the medical and nonmedical services needed to help them achieve their maximum potential.

A medical home is<sup>1, 2</sup>:

- Accessible—Care is provided in the child’s community. All insurance, including Medicaid, is accepted and changes are accommodated.
- Family-Centered—The family is recognized as the principal caregiver and the center of strength and support for children. Unbiased and complete information is shared on an ongoing basis.
- Continuous—The same primary pediatric health care professionals are available from infancy through adolescence. Assistance with transitions (to school, home, and adult services) is provided.
- Comprehensive—Health care is available 24 hours a day, 7 days a week. Preventive, primary, and tertiary care needs are addressed.
- Coordinated—Families are linked to support, educational, and community-based services. Information is centralized.
- Compassionate—Concern for the well-being of the child and family is expressed and demonstrated.
- Culturally Competent—The family’s cultural background is recognized, valued, and respected.

The American Academy of Pediatrics has identified several services that should be provided by medical homes<sup>2</sup>:

- Provision of family-centered care by developing a trusting partnership with families, respecting their diversity, and recognizing that they are the constant in a child's life.
- Sharing clear and unbiased information with the family about the child's medical care and management and about the specialty and community services and organizations they can access.
- Provision of primary care, including but not restricted to acute and chronic care and preventive services (such as breastfeeding promotion and management; immunizations; growth and developmental assessments; appropriate screenings; health care supervision; and patient and parent counseling about health, nutrition, safety, parenting, and psychosocial issues).
- Assurance that ambulatory and inpatient care for acute illnesses will be continuously available (24 hours a day, 7 days a week, 52 weeks a year).
- Provision of care over an extended period of time to ensure continuity. Transitions, including those to other pediatric providers or into the adult health care system, should be planned and organized with the child and family.
- Identification of the need for consultation and appropriate referral to pediatric medical subspecialists and surgical specialists. (In instances in which the child enters the medical system through a specialty clinic, identification of the need for primary pediatric consultation and referral is appropriate.) Primary, pediatric medical sub-specialty, and surgical specialty care providers should collaborate to establish shared management plans in partnership with the child and family and to formulate a clear articulation of the role of each.

- Interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed.
- Provision of care coordination services in which the family, the physician, and other service providers work to implement a specific care plan as an organized team.
- Maintenance of an accessible, comprehensive, central record that contains all pertinent information about the child, preserving confidentiality.
- Provision of developmentally appropriate and culturally competent health assessments and counseling to ensure successful transition to adult-oriented health care, work, and independence in a deliberate, coordinated way.

Thus, in addition to clinical skills, the primary healthcare provider needs to develop knowledge of the condition, care coordination skills, and the ability to work with families as partners.

### *Knowledge of the Condition*

Knowledge of the condition is required, as is that of the medical and nonmedical needs that are associated with it, including:

- Up-to-date information on the medical interventions that are recommended and available.
- Resources and services available, such as Medicaid, Title V Maternal and Child Health Programs, Supplemental Social Security, and Part B and Part H of the Individuals with Disabilities Education Act.
- Eligibility requirements.
- How to access services.

If a provider is not able to take on the role of access and coordination of nonmedical care, he/she should work closely with Part C providers and state special needs case managers to ensure that the appropriate services are provided to the families.

### *Effective Care Coordination*

Effective care coordination activities depend on several factors. First, a healthcare model must be developed and implemented that includes creating a network of reliable pediatric specialists. Medical home providers must be able to provide specialists with an accurate diagnosis or prognosis or a full explanation of the child's symptoms and needs, and incorporate the specialist's findings and recommendations into the child's healthcare plan. The provider also must be able to work with the family to develop a long-term health plan that addresses medical, developmental, and social issues commonly encountered by children with chronic health conditions, and to facilitate access to services and resources.

### *Working with Families*

Because the medical home is ideally a partnership between the provider and the family, the provider must have skills in facilitating this partnership. The medical home provider must be able to acknowledge that the family members are the experts on their child's strengths and needs, to provide complete and unbiased information to the family, and to explore the risks and benefits of various treatment options with special attention to the family's unique set of needs and values. The medical system environment should be set up in such a way that families are comfortable navigating within it. All of these factors will work together to help the provider empower the family to play a critical role in the care coordination process.

The ability to provide culturally competent health care is also necessary for effective partnering with families. This includes three components: 1) awareness of commonly held cultural beliefs and the culturally normative interactive styles in the patient's cultural group; 2) assessment of how the beliefs and behaviors of this cultural group affect the patient or family; and 3) negotiation between the ethnocultural beliefs and practices of the family and those of the culture of bio-medicine<sup>8</sup>. In this process, it is best to assess the cultural beliefs and practices directly from the patient and family, rather than to make assumptions about their race, ethnicity or culture. Family members should be encouraged to describe their cultural characteristics and health care beliefs. The information obtained from the family can then be used in conjunction with information about the groups<sup>9</sup>. Specific suggestions for running an effective medical home are included at the end of this chapter.

## Medical Homes and EHDI

The medical home provider is in an ideal situation to minimize loss to follow-up in EHDI systems by ensuring that patients are screened and encouraged to complete referral screenings and diagnostics. Primary care providers also play key roles in identification of hearing loss that develops later in infancy or childhood, for example by providing ongoing medical assessments and management of children with risk factors (such as chronic otitis media). The primary care provider is also in a position to help connect families to services, and to ensure that families are provided with information about all possible choices so that the family can make informed decisions.

## Medical Home Barriers

Time and reimbursement are the most common barriers to the development of an effective medical home. Children with special health care needs require extra time both in the office (longer physical examinations and more time to collect medical and family histories) and

out of the office (accessing resources and services). Providers often encounter difficulties in receiving reimbursement for this extra time<sup>10</sup>. Other barriers include lack of a referral network, multiple care coordinators, lack of knowledge, and lack of effective communication.

In conclusion, a medical home is an approach to health care for children with special needs in which both the primary care provider and the patient's family play critical roles in the development of an integrated long-term plan to maximize the child's medical, developmental, educational and social outcome. The effectiveness of the medical home process requires cultivation of skills in both the provider and the family, and creation of a partnership between the two.

### **Websites Related to Medical Homes:**

[www.aap.org/advocacy/medhome/AAP.htm](http://www.aap.org/advocacy/medhome/AAP.htm)—American Academy of Pediatrics' Medical Home Page

[www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)—Tools for Assessing and Improving Medical Homes

[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)—National Center of Medical Home Initiatives

[www.nichq.org](http://www.nichq.org)—National Initiative for Children's Healthcare Quality

[www.familycenteredcare.org](http://www.familycenteredcare.org)—Institute for Family Centered Care

[www.ihl.org](http://www.ihl.org)—Institute for Healthcare Improvement

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## Medical Home Tips for Primary Care Providers

- Acknowledge the family's sense of urgency by responding quickly to requests for information, referrals, and the like.
- Offer a flexible schedule for care, including evenings and weekends.
- Assist in maximizing the benefits of health plans.
- Offer flexible payment options.
- Believe that the family's perspective is as important as yours.
- Set your values and preferences aside and operate from those of the family.
- Ask family members how they would like medical and other information provided.
- Ask family members to identify their strengths.
- Share information about the child's condition openly and continually.
- Ask about the family's needs, health, and other concerns during every visit.
- Understand that the child's health care needs are only one part of the family's needs.
- Help family members meet all needs of the child or refer them to someone who can.
- Manage health promotion, injury, and prevention, as well as acute and chronic illness needs.
- Help the family know what to expect.

## Medical Home Tips for Primary Care Providers (continued)

- Support family members when they are faced with difficult or changing situations.
- Encourage family members to learn about how to manage the child's special needs at home.
- Freely share information with other professionals who are involved with the child's care.
- Link the child and family to all necessary providers and services.
- Keep track of all appointments the child has with specialists.
- Create an environment in which family members feel supported and comfortable enough to speak freely.
- Talk with family members about the possibilities for the child's progress.
- Encourage family members to seek support of other families with similar ties and backgrounds.
- Give family members information in their first language.
- Incorporate the family's beliefs and customs into the child's treatment plan.

## Medical Homes Checklist

### *Medical Home Concept*

- Care coordination
- Participation of family members
- Knowledge of the condition
- Knowledge of available services
- A network of pediatric specialists
- Effective communication between providers
- Effective communication between providers and family members
- Cultural competency

### *Medical Homes and EHDI*

- Minimization of loss to follow-up
- Identification of cases of progressive hearing loss
- Management of risk factors
- Connection to services
- Provision of information to family members

### *Medical Home Barriers*

- Time
- Reimbursement
- Lack of referral networks
- Multiple care coordinators
- Lack of knowledge
- Lack of effective communication



# APPENDIX I

## National Goals, Program Objectives, and Performance Measures for the Early Hearing Detection and Intervention (EHDI) Tracking and Surveillance System

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In collaboration with state participants and representatives from other federal and national agencies, CDC developed EHDI program objectives and performance indicators. Numerous sources were used to identify these objectives and indicators, such as state guidelines and the position statements of the Joint Committee on Infant Hearing (JCIH) and the American Academy of Pediatrics (AAP). States are responsible for putting these objectives into a feasible time line.

### Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge

Program Objectives	Performance Indicators
1.1 <i>Universal screening.</i> All birthing facilities will have a universal newborn and infant hearing screening (UNHS) program that screens all newborns. Small hospitals that do not screen newborns will refer infants to a screening program.	a. Number and percent of birthing hospitals in the state that screen at least 98% of infants before discharge. b. Number and percent of small hospitals that do not screen but have plans for referral of infants to a screening program, including designation of responsible staff positions(s) and time line. c. Number and percent of infants screened before hospital discharge. d. Number and percent of infants screened before 1 month of age. e. Number and percent of infants whose families refuse screening.

**Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge (continued)**

Program Objectives	Performance Indicators
<p>1.2 <i>Information on newborn hearing and the screening process.</i> All birthing facilities will have linguistically appropriate and culturally sensitive brochures or other materials to inform parent(s) or guardians of newborns about the newborn hearing and screening process before the infant is screened.</p>	<p>a. Number and percent of pregnant women that received EHDI information before delivery.                      b. Number and percent of new parents that receive EHDI information in the hospital at the time of delivery.                      c. Number and percent of hospitals that provide information packets in Spanish, or other languages spoken by at least 5% of the population.</p>
<p>1.3 <i>Demographic data.</i> All hospitals will collect demographic data such as race/ethnicity, educational level of the mother, and type of insurance covered before hospital discharge.</p>	<p>a. Number and percent of infants in each racial/ethnic group.                      b. Percent of infants whose mothers are in each category of level of education.                      c. Number and percent of mothers in each insurance category.</p>
<p>1.4 <i>Out of hospital births.</i> States will have a mechanism to ensure that infants not born in birthing hospitals will receive a hearing screening.</p>	<p>a. Number and percent of infants born out of hospital.                      b. Number and percent of infants born out of the hospital that received a hearing screening before one month of age.</p>
<p><b>1.5 Financial barriers.</b> Each state will develop a system to reduce/eliminate financial barriers to newborn hearing screening.</p>	<p>a. Published guidelines to reduce financial barriers that include information for parents on how to receive financial help or free screening and/or diagnostic services.                      b. Number of hospitals or other relevant organizations to which the guidelines were distributed, including designation of responsible staff and timelines.</p>
<p><b>1.6 Reporting.</b> Results of the hearing screening will be provided to the infant’s parents and primary care provider (PCP).</p>	<p>a. Forms and stated protocol for providing screening results to parents and PCP are available.</p>

**Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge (continued)**

Program Objectives	Performance Indicators
<p><b>1.7 Linkage and referral to audiologic follow-up.</b> Each state will identify a linkage system to ensure that all infants who do not pass the hearing screening will have appropriate referral for diagnostic evaluation. Referral rates will be 4 percent or less</p>	<p>a. Number and percent of infants that do not pass the initial inpatient or outpatient screening and are referred for diagnostic audiologic evaluation.</p>
<p><b>1.8 Education and training.</b> Hospitals or EHDI program will have a training plan for all service providers, including screeners (inpatient and outpatient), nurses, and physicians.</p>	<p>a. Yearly or semiannual list of training sessions completed (or planned) for screeners, nurses, and physicians.</p>
<p><b>1.9 Screening protocols.</b> Hospitals will have written hearing screening protocols that include standard policies, procedures for screening, and appropriate forms.</p>	<p>a. Copy of hearing screening protocols.</p>

**Goal 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age**

Program Objectives	Performance Indicators
<p><b>2.1 Audiologic evaluation.</b> Audiologists will administer a comprehensive audiologic evaluation to all infants who screen positive for hearing loss before 3 months of age to confirm infant/child hearing loss, including type, configuration, and degree.</p>	<ul style="list-style-type: none"> <li>a. Number and percent of infants who screened positive and received a comprehensive audiologic evaluation before 3 months of age.</li> <li>b. Number and percent of infants with bilateral or unilateral hearing loss.</li> <li>c. Number and percent of infants with permanent conductive, sensorineural, or auditory dys-synchronous hearing loss.</li> <li>d. Number and percent of infants with mild, moderate, severe, moderately-severe, or profound hearing loss.</li> <li>e. Number and percent of infants referred for audiologic evaluation who were lost to follow-up.</li> <li>f. Number and percent of infants at risk of developing late onset hearing loss who were lost to follow-up.</li> <li>g. Number and percent of infants referred for audiologic evaluations who were not screened for hearing loss.</li> </ul>
<p><b>2.2 Evaluation protocols.</b> Each state will develop and make accessible protocols and guidelines for appropriate diagnostic audiologic evaluation and recommendations for management (e.g., amplification, rehabilitation). These guidelines will be developed with input from state and local audiologists and based on current national guidelines.</p>	<ul style="list-style-type: none"> <li>a. Documented list of acceptable measures to be included in the test battery for the identification of hearing loss and minimum frequency of evaluation to monitor the hearing sensitivity of all infants and children identified with hearing loss and all infants and children identified at risk for late onset, progressive, or acquired hearing loss.</li> <li>b. Copy of diagnostic management (e.g. amplification, rehabilitation) protocol that is based on current national guidelines (JCIH, ASHA, AAA).</li> <li>c. Documentation of availability of protocols for audiologists in a variety of formats.</li> </ul>

**Goal 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age (continued)**

Program Objectives	Performance Indicators
<p><b>2.3 List of diagnostic audiologic providers.</b> Each state will maintain a current resource list of diagnostic centers and/or pediatric audiologists who have experience and expertise in administering diagnostic audiologic evaluations for infants, according to the protocol and guidelines.</p>	<p>a. List of diagnostic centers and audiologists that have experience or expertise in conducting pediatric audiologic assessments.  b. Number of centers and audiologists that have appropriate equipment for diagnostic evaluation of infants.  c. Number of hospitals or referral personnel that maintain a list of diagnostic centers or audiologists.</p>
<p><b>2.4 Linkage to appropriate follow-up.</b> Each state will identify a linkage system to ensure that families of infants identified with hearing loss will have appropriate referral to medical, audiologic, and intervention services, according to state resources.</p>	<p>a. Number and percent of infants identified with hearing loss referred to medical specialists, such as otolaryngologists, ophthalmologists, and geneticists.  b. Number and percent of infants with hearing loss who are referred to early intervention services, including counseling and support services.  c. Number and percent of infants with hearing loss who are referred to ongoing audiologic evaluations and services.</p>
<p><b>2.5 Education and training for audiologists.</b> Each state will develop an education/ training plan for audiologists to ensure competency in pediatric evaluation, management, and family counseling.</p>	<p>a. Documented training plan for audiologists.  b. Number of audiologists trained.</p>
<p><b>2.6 Education and Training for other providers.</b> Each state will develop an education and training plan for primary care providers, public health nurses, and others on the importance and process of audiologic evaluation.</p>	<p>a. Documented training plan for other providers.  b. Number of professionals trained.</p>
<p><b>2.7 Information on the audiologic evaluation process.</b> Parents and guardians will be informed in a culturally sensitive and language-appropriate manner about the diagnostic audiologic evaluation process and report.</p>	<p>a. Documentation of language-appropriate materials and interpreter services to describe audiologic services and reports.  b. Documented plans for disseminating materials.  c. Number of materials distributed.</p>

**Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention)**

Program Objectives	Performance Indicators*
<p><b>3.1 Medical services.</b> All infants identified with hearing loss will receive appropriate medical services, such as primary care, visual screening, genetic services, and counseling before 6 months of age.</p>	<p>a. Number and percent of infants with hearing loss who received appropriate medical services before 6 months of age from: primary care, otolaryngologists, ophthalmologists, and geneticists/genetic counselors.</p>
<p><b>3.2 Early intervention services.</b> Each state will ensure that all infants and children with documented hearing loss will receive appropriate early intervention services from Part C or other state approved intervention services. Service coordination will be provided to eligible children.</p>	<p>a. Number and percent of infants with hearing loss who were enrolled in an intervention program before 6 months of age                      b. Number and percent of infants and children with hearing loss who received family support information about early intervention services.                      c. Number and percent of eligible infants and children categorized by hearing loss who have a signed IFSP or an equivalent intervention plan.                      d. Number and percent of infants who are lost to follow-up after identification.                      e. Number and percent of infants with hearing loss eligible for Part C services with mild hearing loss, moderate hearing loss; moderately-severe hearing loss, severe hearing loss, or profound hearing loss.</p>

\*Some states may need to differentiate between Part C eligible and non-eligible infants.

**Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention) (continued)**

Program Objectives	Performance Indicators
<p><b>3.3 Audiologic services.</b> All infants identified with hearing loss will receive appropriate audiologic services before 6 months of age.</p>	<ul style="list-style-type: none"> <li>a. Documentation that confirms that families of children with hearing loss received information on communication and amplification options.</li> <li>b. Documentation of plan for management of each infant's and child's assistive technology that includes, at a minimum, use of probe microphone measures and recommendations for frequency of evaluation.</li> <li>c. Documentation of protocols and guidelines for managing the aural habilitation or rehabilitation of each infant or child.</li> <li>d. Number and percent of infants fitted with personal amplification before 6 months of age.</li> </ul>
<p><b>3.4 Policy statement for stakeholders.</b> Each state will adopt and distribute as appropriate a policy regarding the rights of every family to choose the communication modes and methods that are most appropriate for their child.</p>	<ul style="list-style-type: none"> <li>a. Documentation of procedural safeguards regarding the rights of families when choosing a communication mode for their children.</li> <li>b. List of resources and contacts providing information about various communication options to enable families to make more informed decisions.</li> <li>c. Documented plans for distributing the resource list and procedural safeguards to families identified by the newborn hearing screening program.</li> </ul>

**Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention) (continued)**

Program Objectives	Performance Indicators
<p><b>3.5 Resource guide.</b> All states will develop a comprehensive, family-friendly Resource Guide that will include: material from a variety of sources; a list of relevant web sites; a list of state contact people. The Guide will be available in print as well as on a web site and in major languages used in the state, pending available resources.</p>	<p>a. Number and percent of parents and guardians of infants who have a confirmed hearing loss that reached 6 months of age within the last calendar year that received a copy of the state resource guide.</p> <p>b. Documentation of resource guides in any language spoken by 5% or more of the population in that state.</p> <p>c. The state resource guide will include a list of questions for parents to ask in assessing the philosophy and practices of programs they consider for their child.</p>
<p><b>3.6 Membership of IFSP or other intervention team.</b> All families who have a child with identified hearing loss should have an individual on their intervention team who has knowledge, experience, and expertise with the issues related to children who are deaf or hard of hearing.</p>	<p>a. Number and percent of intervention teams that include individuals with professional preparation and experience working with children with hearing loss.</p>
<p><b>3.7 Education and training.</b> States will provide opportunities to Part C and other intervention services to receive training on specific issues related to deafness and hearing loss.</p>	<p>a. Documentation of implemented and planned training sessions for Part C or other intervention service providers.</p>
<p><b>3.8 Quality intervention systems.</b> States shall make sure that high quality early intervention systems are available, including those that meet the needs of diverse populations and children with additional disabilities.</p>	<p>a. List of intervention services that describes available services for diverse populations.</p> <p>b. Documentation of services for children with hearing loss who also have other disabilities.</p>

**Goal 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention) (continued)**

Program Objectives	Performance Indicators
<p><b>3.9 Recommendations for early intervention providers.</b> States shall develop a set of recommendations for early intervention providers who work with children who are deaf or hard of hearing and their families that include:</p> <ul style="list-style-type: none"> <li>• identification of objective sources of information for families to learn about communication options,</li> <li>• guidelines for monitoring the communication and social skill development of the child with hearing loss at 6-month intervals,</li> <li>• identification by each early intervention program of personnel within their staffs who are specialists in deaf and hard of hearing issues,</li> <li>• process for linking to family-to-family support within an early intervention system,</li> <li>• list of preschool program options that are particularly prepared to serve children who are deaf or hard of hearing, and inclusion of this information in the preparation of the family for transition at age 3 years.</li> </ul>	<ul style="list-style-type: none"> <li>a. Documented distributions of a resource guide that presents balanced information on communication options.</li> <li>b. Documented test scores for communication and social skill development at 6-month intervals.</li> <li>c. Documentation of annual updated guidelines.</li> <li>d. Number and percent of families referred to and involved in parent-to-parent support program.</li> </ul>
<p><b>3.10 Parent participation.</b> Each state will ensure families of children with hearing loss have an opportunity to actively participate in the EHDI system.</p>	<ul style="list-style-type: none"> <li>a. Number and percent of parents involved in their child’s program planning, evaluation, or monitoring.</li> <li>b. Number and percent of parents on the EHDI Advisory Board.</li> </ul>

**Goal 4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time**

Program Objectives	Performance Indicators
<p><b>4.1 Risk factors:</b> Each hospital, audiologist and other providers, will identify infants with risk factors for hearing loss and transmit the information to state.</p>	<p>a. Number and percent of infants with one or more risk factors.</p>
<p><b>4.2 Monitoring of at-risk infants.</b> Each state will have a mechanism in place to monitor the hearing status of infants at risk for late onset and progressive hearing loss.</p>	<p>a. Number and percent of infants with risk factors who are re-screened by 6 months.</p>
<p><b>4.3 Acquired hearing loss.</b> Each state will have a mechanism in place to identify and provide follow-up services for infants and children with acquired hearing loss.</p>	<p>a. Number and percent of infants and children identified with acquired hearing loss.</p>

**Goal 5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics**

Program Objectives	Performance Indicators
<p><b>5.1 Medical Home.</b> Each infant with a confirmed hearing loss will have an identified primary care provider before 3 months of age.</p>	<p>a. Number and percent of infant records that include name of the infant’s primary care provider. b. Documentation that the results of the infant’s audiologic evaluation were sent to their primary care provider.</p>
<p><b>5.2 Collaboration with early intervention.</b> Each medical home will collaborate with the early intervention system and the family to develop a plan to connect families to advocacy groups, parent support networks, and parent-to-parent support.</p>	<p>a. Documentation in each family plan or IFSP of collaboration between the early intervention systems and the medical home.</p>
<p><b>5.3 Unbiased information.</b> Each state will develop resources that can be shared with the medical homes and families to provide unbiased information.</p>	<p>a. Documentation that the Resource Guide describing unbiased information regarding early intervention strategies is provided to physicians and other primary care providers.</p>
<p><b>5.4 Education.</b> In partnership with parents of children with hearing loss, states will develop a plan to provide education about the state EHDI program to medical homes.</p>	<p>a. Documentation of plan to provide information on the EHDI program to the Medical Home of each infant and child. b. Number and percent of each type of medical home (physician, midwife, etc.) that receives written information or attends a session about the EHDI Program, or both.</p>
<p><b>5.5 Parental input.</b> Each state will have a mechanism for obtaining parent feedback and including parents in the process of development and evaluation processes for the medical home.</p>	<p>a. Number of parents participating in the development and evaluation of the medical home. b. Results of survey or other mechanism to obtain parent feedback</p>
<p><b>5.6 Continuous care.</b> Each state will have a mechanism for identifying and tracking the infant’s primary care provider at key intervals, regardless of insurance status.</p>	<p>a. Number and percent of infant records with updated documentation of who the primary care provider is at birth, initial diagnosis, enrollment in early intervention and at each IFSP contact.</p>

## Goal 6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up

Program Objectives	Performance Indicators
<p><b>6.1 Comprehensive system.</b> Each state will have a computerized system that maintains current information on hearing screening for every infant, evaluation for all infants and children who do not pass the screening and interventions for every infant and child from birth through 5 years of age with hearing loss.</p>	<p>a. Written description of computerized system b. Printouts and reports of screening, evaluation, and intervention data.</p>
<p><b>6.2 Policies and procedures.</b> Each state will have written policies and procedures regarding operation of the EHDI Tracking and Surveillance System.</p>	<p>a. Documentation of policies and procedures manual.</p>
<p><b>6.3 Privacy and confidentiality.</b> Each state will develop policies, procedures, and informed consent requirements regarding privacy and confidentiality of data in the EHDI Tracking and Surveillance System.</p>	<p>a. Documentation of policy and procedures on informed consent requirements.</p>
<p><b>6.4 Include all births.</b> Each state will ensure that all live births in the state are included in the state EHDI Tracking and Surveillance System by matching with the state's birth certificates registry as allowed by state policy.</p>	<p>a. Number of live-born infants. b. Documentation of Number and percent of matches with vital records. c. Number and percent of infants screened.</p>
<p><b>6.5 Risk factors for hearing loss.</b> The state EHDI Tracking and Surveillance System will ascertain risk factors for hearing loss for every infant by linkage with other state data systems, such as hospital records, birth certificates, birth defects, metabolic screening, immunizations, etc.</p>	<p>a. Number and percent of infants with risk factors. b. Number and type of risk factors for each infant.</p>

## Goal 6. Every state will have a complete EHDI Tracking and Surveillance System that will minimize loss to follow-up (continued)

Program Objectives	Performance Indicators
<p><b>6.6 Newborn hearing screening results.</b> The state EHDI Tracking and Surveillance System will capture all hearing screening results at birthing hospital within a week after discharge or transfer.</p>	<p>a. Report on number and percent of infants screened that includes results for each ear, technology used, and age at screening.</p>
<p><b>6.7 Reporting mechanism for health care providers.</b> Each state will provide a mechanism for hospitals, audiologists and other health care providers to report hearing screening results, evaluations and interventions.</p>	<p>a. Number of health care providers that have protocols for reporting hearing screening results, evaluations and interventions. b. Number of health care providers reporting hearing screening results to the state.</p>
<p><b>6.8 Identifying children who need screening and follow-up.</b> The state EHDI Tracking and Surveillance System will be able to identify, on a [weekly] basis, all infants and children who need initial hearing screening, repeat testing, evaluation, follow-up, or intervention.</p>	<p>a. Number and percent of infants and children needing follow-up who:</p> <ul style="list-style-type: none"> <li>• were referred for second screening</li> <li>• missed screening</li> <li>• need a repeat screening</li> <li>• were referred for diagnostics</li> <li>• were referred for early intervention</li> </ul> <p>b. Number and percent of infants and children who received follow-up.</p>
<p><b>6.9 Access to information.</b> The state EHDI Tracking and Surveillance System will allow case managers and authorized health care providers to access relevant information about infants and children.</p>	<p>a. Written plan to allow case managers and authorized health-care providers to access relevant information.</p>

**Goal 7. Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI Goals and Objectives**

Program Objectives	Performance Indicators
<p><b>7.1 Advisory Committee.</b> Each state’s advisory committee will meet routinely to provide guidance on the EHDI system. The committee should include professionals, individuals with hearing loss, families with children who have permanent hearing loss, and others to provide guidance on the development and evaluation of the EHDI system.</p>	<p>a. List of Advisory Committee members. b. Minutes of Advisory Meetings</p>
<p><b>7.2 Monitoring and evaluation.</b> Each state EHDI program will develop a program evaluation plan in collaboration with the program Advisory Committee to ensure progress towards national and state program goals and objectives.</p>	<p>a. Annual evaluation reports that include accomplishments of national and state program goals and objectives.</p>
<p><b>7.3 Feedback from families.</b> The state EHDI program will obtain feedback from parents on the EHDI process</p>	<p>a. Copy of survey of parent concerns and issues. b. Documented results of parent survey to stakeholders.</p>
<p><b>7.4 Surveillance of follow-up services.</b> Each state will ensure that infants and children with hearing loss receive ongoing and appropriate follow-up services.</p>	<p>a. Number and percent of infants and children with hearing loss that received appropriate ongoing medical services from primary care, otolaryngologists, ophthalmologists, geneticists and genetic counselors. b. Number and age of infants and children fitted with implants. c. Number and percent of infants and children using each mode of communication, e.g., sign language, oral, cued speech at 6-month intervals. d. Number and percent of infants and children achieving communication and social skills scores commensurate with their cognitive abilities age at 1, 3, 5, and 7 years of age. e. Number and percent of infants and children with hearing aids that receive follow-up visits at 2-month intervals until age 2 years and 3-month intervals until age 3.</p>

## APPENDIX II

### EHDI Abbreviations and Acronyms

AAA	American Academy of Audiology
AABR	Automated Auditory Brainstem Response
AAFP	American Academy of Family Physicians
AAOHSNS	American Academy of Otolaryngology-Head and Neck Surgery
AAP	American Academy of Pediatrics
ABR	Auditory Brainstem Response
ACOG	American College of Obstetricians and Gynecologists
AEP	Auditory Evoked Potentials
AMA	American Medical Association
AMCHP	Association of Maternal and Child Health Programs
ANA	American Nurses Association
ASDC	American Society for Deaf Children
ASHA	American Speech-Language-Hearing Association
BAER	Brainstem Auditory Evoked Response
BSER	Brainstem Evoked Response
BTNRH	Boys Town National Research Hospital
CBC	Center for Beneficiary Choices (new under CMMS)
CDC	Centers for Disease Control and Prevention
CEC	Council for Exceptional Children
CHCP	Child Health Care Providers
CMM	Center for Medicare Management (new under CMMS)
CMMS	Centers for Medicare and Medicaid Services (new agency replacing HCFA—see also CMM, CBC, CMSO)
CMSO	Center for Medicaid and State Options (new under CMMS)

CMV	Cytomegalovirus
CPT	Current Procedural Terminology
CSHCN	Children with Special Health Care Needs
DHHS	Department of Health and Human Services
DPOAE	Distortion Product Otoacoustic Emissions
DRF	Deafness Research Foundation
DSHPHWA	Directors of Speech and Hearing Programs in State Health and Welfare Agencies
EHDI	Early Hearing Detection and Intervention
EOAE	Evoked Otoacoustic Emissions
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FACCT	The Foundation for Accountability
FERPA	Family Educational Rights and Privacy Act
FICC	Federal Interagency Coordinating Council
HCFA	former Health Care Financing Administration (now see CMMS)
HEDIS	Health Plan Employer Data and Information Set
HIPAA	Health Insurance Portability and Accountability Act of 1996
HRSA	Health Resources and Services Administration
ICC	Interagency Coordinating Council
ICD	International Classification of Diseases
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Educational Plan
IFSP	Individualized Family Service Plan
JCAHO	Joint Committee on Accreditation in Health Organizations
JCIH	Joint Committee on Infant Hearing
MCHB	Maternal and Child Health Bureau

MDNC	Marion Downs National Center
NACHO	National Association of County Health Officers
NAD	National Association of the Deaf
NBS	Newborn Screening
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCCC	National Center for Cultural Competence
NCHAM	National Center for Hearing Assessment and Management
NCHH	National Campaign for Hearing Health
NCMHI	National Center for Medical Homes Initiatives
NCQA	National Center for Quality Assurance
NECTAC	National Early Childhood Technical Assistance Center
NIDCD	National Institute on Deafness and Other Communicative Disorders
NIH	National Institutes of Health
NOMS	National Objective Measurement System
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitative Services
PCHP	Primary Health Care Providers
PCP	Primary Care Providers
PHI	Protected Health Information
PKU	Phenylketonuria
PTIC	Parent Training Information Centers
RFP	Request for Proposal
SABR	Screening Auditory Brainstem Response
TEOAE	Transient Evoked Otoacoustic Emissions
UNHS	Universal Newborn Hearing Screening
VNA	Visiting Nurse Association

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WIC

Women Infants and Children

## APPENDIX III

### Surveillance Data Items

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#### Data items for state-based Early Hearing Detection and Intervention (EHDI) tracking database

First draft created by Roy Ing, June 11, 2001; subsequent drafts updated by Data Committee during monthly conference calls, July 2001 through July 2002

#### *Purpose*

To create a comprehensive list of data items that can be used as a guide for building a state-based EHDI tracking system

This draft is intended as a guideline for states or facilities developing a newborn hearing program. Data items identified are classified as follows:

- M = Minimum data item**—data item recommended for all state data systems; the set of data items that are required for follow-up on universal newborn hearing screening and for full reporting on national EHDI goals.
- C = Core data item**—data item recommended for complete state-level data system, including basic data needed for program evaluation.
- E = Enhanced data item**—additional data item useful for clinicians, enhanced tracking, or research.

### *Audience*

State EHDI coordinators

Information systems developers interested in state-based EHDI tracking system

Facilities providing hearing screening, diagnosis, intervention, or research related to state or national EHDI programs

### *Notes*

Assumes a centralized, state-level data system (standalone or linked to other data systems) with child-specific data

**The current draft does not yet include the following (to be added in a later draft):**

- Categories or codes for all data items

- Complete listing in the Measure Component column of which data items are intended for use in which summary statistics

- Recommended sources of data

- Data item specifically indicating Amplification Type (Monaural, Binaural, unknown)

- Data item indicating if Referral was sent that requested assistance locating a child lost to follow-up.

### *Information or specifications this document is not intended to include*

- Comprehensive information about hospital screening programs

- Information about the state's EHDI program or tracking system

- Requirements for the summary statistics and reports to be generated from this database

- Information about privacy, confidentiality, and security of data

Information about linkage with other data systems or which of these items could come from other data systems

All data items needed for summary statistics for hospitals and other providers may be required to report to the state

<b>Outline</b> —Record types described are suggestions; database design may differ from state to state.	<b>Possible Record Type</b>
<p><b>Information about facilities (places) and programs</b></p> <ul style="list-style-type: none"> <li>Information about BIRTHING HOSPITAL OR FACILITY</li> <li>Information about HEARING TESTING / EVALUATION CLINIC OR FACILITY</li> <li>Information about HEARING LOSS FOLLOW-UP FACILITY</li> <li>Information about HEARING LOSS FOLLOW-UP PROGRAM</li> <li>Information about GENETIC TESTING LABORATORY</li> </ul>	Facility Record
<p><b>Information about providers</b></p> <ul style="list-style-type: none"> <li>Information about PERSON CONDUCTING HEARING SCREENING (SCREENER)</li> <li>Information about AUDIOLOGIST</li> <li>Information about PHYSICIAN</li> <li>Information about GENETIC COUNSELOR</li> <li>Information about CASE MANAGER FOR CHILD WITH HEARING LOSS</li> <li>Information about HEARING LOSS INTERVENTION SPECIALIST</li> </ul>	Provider Record
<p><b>Information about child and family</b></p> <ul style="list-style-type: none"> <li>Information about FAMILY (mother, father, relative, caregiver)</li> <li>Basic information about CHILD</li> <li>Information about CHILD’S RISK FACTORS</li> </ul>	<p>Family Record</p> <p>Child Record</p> <p>Child Record</p>
<p><b>Information about events</b></p> <ul style="list-style-type: none"> <li>Information about child’s BIRTH HOSPITALIZATION</li> <li>Information about each SCREENING (FIRST OR RE-SCREEN) TESTS performed on child</li> <li>Information about each DIAGNOSTIC HEARING EVALUATION performed on child</li> <li>Information about EARLY INTERVENTION SERVICES received by each child with HEARING LOSS</li> <li>Information about MEDICAL EVALUATION AND MEDICAL INTERVENTION received by each child with HEARING LOSS</li> <li>Information about GENETIC TESTING of each child with HEARING LOSS and GENETIC COUNSELING for families</li> <li>Information about SPEECH AND LANGUAGE DEVELOPMENT of each CHILD with HEARING LOSS</li> </ul>	Child Record
<p><b>Information about hearing screening and follow-up status of child</b></p> <ul style="list-style-type: none"> <li>Types of COMMUNICATIONS TO PARENTS AND PROVIDERS</li> <li>Summary report of STATUS of SCREENING, EVALUATION, HEARING LOSS and INTERVENTION of child</li> </ul>	Program Reports

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**Abbreviations****Data Need categories:**

M = Minimum data item—data item recommended for all state data systems and required to report fully on national EHDI goals.

C = Core data item—data item recommended for complete state-level data system, including basic data needed for program evaluation.

E = Enhanced data item—additional data item useful for clinicians, enhanced tracking, or research.

**Other Abbreviations:**

DSHPSHWA = Directors of Speech and Hearing Programs in State Health and Welfare Agencies

ICD = International Classification of Diseases; codes used to designate diagnoses, conditions of newborn, causes of death, etc.

JCIH = Joint Committee on Infant Hearing

UNHS = Universal Newborn Hearing Screening

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**DRAFT**  
**Information about**  
**BIRTHING HOSPITAL OR FACILITY**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
1	M	Hospital or birthing facility (unique identifier).			EHDI 1.1; DSHPSHWA 10, 11, 13
2	C	Hospital or facility name			
3	C	Name of contact person		Not Screener	
4	C	Hospital or facility address, phone			
5	C	Type of facility (hospital, birthing facility)		Core but can get from another source	
6	C	Number of births for each (previous) year		Core but can get from another source	
7	C	Number of births for each month Core but can get from another source			
8	M	Number of newborns screened		Provided to national or out-of-state databases without hospital identifier.	
9	M	Newborn hearing screening status	Universal / High risk infants only / Some / None	Provided to national or out-of-state databases without hospital identifier.	
10	M	Number of families that refuse screening		Provided to national or out-of-state databases without hospital identifier.	
11	E	Out-patient infant hearing screening in hospital	Yes/No	at hospitals, not pediatrician's office need contact at each	
12	C	Infant hearing screening coordinator (identifier: name, address, phone, FAX, email)		hospital (not screener)	
13	E	Are translation services available?	Yes/No	Need to decide how these should be measured.	
14	E	For what languages are translation services available?			

**Information about  
BIRTHING HOSPITAL OR FACILITY (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
15	M	Are alternate forms of educational materials available?	Availability for languages where 5% or more of population represented	E.G., all hospitals in Georgia have access to materials in the four most frequently spoken languages from the UNHS program; availability of materials is unknown.	EHDI 1.2
16	E	Are culturally sensitive forms of educational materials available?	Yes/No		
17	E	For what languages are educational materials available?			

**Information about  
HEARING TESTING/EVALUATION CLINIC OR FACILITY**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
18	C	Hearing testing/ evaluation facility (unique identifier)			
19	C	Health facility (facility) name			
20	C	Contact Person		Primary contact person for this facility - Audiologist with pediatric experience	
21	C	Health facility address, phone			
22	C	Type of facility	Hospital, clinic, office		
23	E	Types of hearing testing services		May be core for states with rural diagnostic centers, or states just starting programs	

**Information about  
HEARING TESTING/EVALUATION CLINIC OR FACILITY (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
24	E	Are translation services available?	Yes/No		
25	E	For what languages are translation services available?			
26	E	Are alternate forms of educational materials available?	Yes/No	Need to determine how this is to be measured.	
27	E	Are culturally sensitive forms of educational materials available?	Yes/No		
28	E	For what languages are educational materials available?			

**Information about  
HEARING LOSS FOLLOW-UP FACILITY**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
29	C	Hearing loss follow-up facility (unique identifier)		Needs to be repeated for each facility	
30	C	Program name			
31	C	Health facility (facility) name			
32	C	Health facility address, phone			
33	C	Primary Contact (Aud or director)			
34	C	Type of facility (hospital, clinic, etc)			
35	C	Types of hearing loss services			
36	E	Are translation services available?	Yes/No		

**Information about  
HEARING LOSS FOLLOW-UP FACILITY (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
37	E	For what languages are translation services available?			
38	E	Are alternate forms of educational materials available?	Yes/No		
39	E	Are culturally sensitive forms of educational materials available?	Yes/No		
40	E	For what languages are educational materials available?			

**Information about  
HEARING LOSS FOLLOW-UP PROGRAM**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
41	E	Hearing loss follow-up program (unique identifier)			
42	E	Program name			
43	E	Health facility (identifier)			
44	E	Contact person (identifier)			
45	E	Type of service	Amplification, audiology, child/child group, home visits, medical ophthalmology, genetics, neurology, nursing, parent-infant group, parent-parent group, parent-toddler group, parent education, service coordination, speech or language, community outreach, referral, other	Type of service will differ by category of service; need agreement on categories and types within category. Each child may have several categories of service and several types of service and/or types of providers within each category.	

**Information about  
HEARING LOSS FOLLOW-UP PROGRAM(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
46	E	Type of provider	Primary care provider, specialty physician, audiologist, physician's assistant, nurse practitioner, nurse, health educator, paraprofessional		
47	E	Category of service			
48	E	Referral offered?	Yes/No		
49	E	If refer, where?			
50	E	Description of program			
51	E	Comments			
52	E	Are translation services available?	Yes/No		
53	E	For what languages are translation services available?			
54	E	Are alternate forms of educational materials available?	Yes/No		
55	E	Are culturally sensitive forms of educational materials available?	Yes/No		
56	E	For what languages are educational materials available?			

**Information about  
GENETIC TESTING LABORATORY**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
57	C	Laboratory (unique identifier)		Genetic testing lab data not in minimum data set	
58	C	Laboratory name			
43	C	Health facility (identifier)			
59	C	Contact person (identifier)			
60	C	Contact name			
61	C	Contact telephone number, fax, e-mail			
62	E	Contact mailing address			
63	C	Types of genetics testing			

**Information about  
PERSON CONDUCTING HEARING SCREENING (SCREENER)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
64	E	Person (unique identifier)		Screeener data is hospital-level data; not in minimum data set.	
65	E	Person's name (Last, first, middle)			
66	E	Person's social security number			
67	E	Person's profession in facility (e.g., nurse)			
68	E	Person's professional license number			
43	E	Primary health facility (identifier)			
69	E	Person's work phone number(s), FAX, email			
70	E	Person's training or qualifications	M.D. / M.S. / M.A. / CCC-A / other		

**Information about  
AUDIOLOGIST**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
71	C	Audiologist (unique identifier)			
72	E	Audiologist's name (Last, first, middle)			
73	E	Audiologist's social security number		SS numbers may not be available for providers. If used as unique identifiers, they may need to be encrypted for a state-level system. (Enhanced data item.)	
74	E	Audiologist's professional license number			
75	C	Audiologist's primary health facility (identifier)			
76	C	Audiologist's address, phone, FAX, email			
77	E	Audiologist's qualifications	M.D. / M.S. / M.A. / CCC-A / other		
78	E	Audiologist performing pediatric audiologic evaluation?			
79	M	Does audiologist follow state protocols?	Yes/No		EHDI 2.3

**Information about  
PRIMARY CARE PROVIDER**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
80	C	Physician (unique identifier)			
81	C	Physician's name (Last, first, middle)			
82	E	Physician's social security number		SS numbers may not be available for providers. If used as unique identifiers, they may need to be encrypted for a state-level system. (This an Enhanced data item.)	
83	E	Provider's medical license number			
84	M	Physician's primary board-certified specialty	Pediatrician / Family Practice / ENT / Eye / Pediatric neurologist / Plastic Surgery / Surgery / Other		EHDI 3.1
85	E	Physician's other board-certified specialties	Pediatrician / Family Practice / ENT / Eye / Pediatric neurologist / Plastic Surgery / Other		
86	E	Physician's sub-specialty related to hearing evaluation and intervention	Dysmorphology, geneticist, pediatrician, ENT, surgery, other		
87	M	This physician represents child's Medical Home		This record must link with child's record for physician who represents medical home.	
88	C	Services provided: Genetic testing			
89	C	Services provided: Genetic counseling			
90	C	Services provided: Hearing testing			

**Information about  
PRIMARY CARE PROVIDER(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
91	C	Services provided: Diagnosis of syndromes and disorders			
92	C	Services provided: Hearing aids			
93	C	Services provided: FM systems			
94	C	Services provided: Cochlear implants			
95	C	Services provided: Speech therapy			
96	C	Services provided: Other (specify)			
97	C	Primary health facility (identifier)			
98	C	Provider's address, phone, FAX, email			

**Information about  
GENETIC COUNSELOR**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
99	C	Genetic counselor (unique identifier)			
100	C	Provider's name (Last, first, middle)			
101	E	Provider's social security number		SS numbers may not be available for providers. If used as unique identifiers, they may need to be encrypted for a state-level system. (Enhanced data item.)	
102	C	Provider's profession	Genetic counselor / etc		

**Information about  
GENETIC COUNSELOR(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
103	E	Provider's state license number			
104	E	Provider's qualifications			
105	C	Services provided: Genetic testing			
106	C	Services provided: Genetic counseling			
107	C	Services provided: Other (specify)			
108	C	Primary health facility (identifier)			
109	C	Provider's address, phone, FAX, email			

**Information about  
CASE MANAGER FOR CHILD WITH HEARING LOSS**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
110	C	Person (unique identifier)			
111	C	Person's name (Last, first, middle)			
112	E	Person's social security number		SS numbers may not be available for providers. If used as unique identifiers, they may need to be encrypted for a state-level system. (This an Enhanced data item.)	
113	C	Health facility (identifier)			

**Information about  
CASE MANAGER FOR CHILD WITH HEARING LOSS(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
114	C	Person's address, phone, FAX, email			
115	C	Person's role(s) in hearing loss intervention/intervention			

**Information about  
HEARING LOSS INTERVENTION SPECIALIST**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
116	C	Provider (unique identifier)			
117	C	Provider's name (Last, first, middle)			
118	C	Provider's social security number			
119	C	Provider's profession	Teacher of D/HH / PT / OT / Other		
120	C	Provider's professional license number			
121	C	Provider's qualifications in infant hearing intervention			
122	C	Health facility (identifier)			
123	C	Person's address, phone, FAX, email			
124	C	Types of hearing loss intervention services			
125	E	Competence level in hearing loss intervention (Degrees / Endorsement / Certification)	(Degrees / Endorsements / Certification)		

**Information about  
FAMILY (mother, father, relative, caregiver)**

Item #	Data Need	Data item description	Categories or codes	Notes	Measure Component
126	M	Child (unique identifier)			
		CAREGIVER INFORMATION		Primary caregiver for infant; will be same as biological mother in most cases	
127	C	Caregiver's name			
128	M	Caregiver's gender		These items are minimum dataset items for the one person who is expected to have the most influence on hearing screening and follow-up and language development. This is usually the biological mother, but not always.	
129	M	Caregiver's date of birth			EHDI 1.3
130	M	Caregiver's ethnicity	Hispanic/Latino or not Hispanic		EHDI 1.3
131	M	Caregiver's race	American Indian or Alaska Native/ Asian/ Black or African American; Native Hawaiian or Other Pacific Islander; White		EHDI 1.3
132	C	Caregiver's education			EHDI 1.3
133	C	Caregiver's primary language			
134	C	Does Caregiver speak English	Yes/No		
		MOTHER INFORMATION		May be the same as the caregiver record.	
135	C	Biological Mother's unique identifier		Birth certificate may not provide if the child is adopted.	

**Information about  
FAMILY (mother, father, relative, caregiver)(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
136	C	Mother's name (Last, first, middle)			
137	E	Mother's maiden name			
138	E	Mother's social security number		Birth certificate may not provide.	
139	C	Mother's date of birth			
140	C	Mother's ethnicity	Hispanic/Latino or not Hispanic		
141	C	Mothers race	American Indian or Alaska Native/ Asian/ Black or African American; Native Hawaiian or Other Pacific Islander; White		
142	C	Mother's education			
143	C	Mother's language			
144	C	Does Mother speak English	Yes/No		
145	C	Mother's residence address			
146	C	Mother's phone number (home or work)	(family phone)		
147	E	Mother's other phone numbers; cell or mobile phone number	(family phone)		
148	C	Mother's county of residence			
149	C	Mother's mailing address			
150	E	Mother's email address			
151	E	Mother's fax number			
<b>FATHER INFORMATION</b>					
152	E	Biological Father's unique identifier		Birth certificate may not provide if the child is adopted.	

**Information about  
FAMILY (mother, father, relative, caregiver)(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
153	E	Father's name (last, first, middle)			
154	E	Father's social security number		Birth certificate may not provide.	
155	E	Father's date of birth			
156	E	Father's ethnicity	Hispanic/Latino or not Hispanic		
157	E	Father's race	American Indian or Alaska Native/ Asian/ Black or African American; Native Hawaiian or Other Pacific Islander; White		
158	E	Father's education			
159	E	Father's language			
160	E	Father's current address			
161	E	Father's phone number (home OR work)			
162	E	Father's other phone numbers; cell or mobile phone number			
163	E	Father's county of residence			
164	E	Father's mailing address			
165	E	Father's email address			
<b>GUARDIAN INFORMATION</b>					
166	C	Guardian's unique identifier			
167	E	Guardian's name			

**Information about  
FAMILY (mother, father, relative, caregiver)(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
168	C	Guardian's relationship to child			
169	E	Guardian's date of birth			
170	E	Guardian's ethnicity	Hispanic/Latino or not Hispanic		
171	E	Guardian's race	American Indian or Alaska Native/ Asian/ Black or African American; Native Hawaiian or Other Pacific Islander; White		
172	E	Guardian's education			
173	E	Guardian's language			
174	C	Guardian's address			
175	C	Guardian's county of residence			
176	C	Guardian's phone number			
177	E	Guardian's other telephone numbers			
178	E	Guardian's e-mail address			
179	E	Comments on Guardian information			
		CONTACT INFORMATION			
180	E	Contact's relationship to child			
181	E	Contact's role (e.g. baby sitter)			
182	E	Contact's name (last, first, middle)			

**Information about  
FAMILY (mother, father, relative, caregiver)(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
183	E	Contact's ethnicity	Hispanic/Latino or not Hispanic		
184	E	Contact's language			
185	E	Contact's current address, phone, email			
186	E	Contact's county of residence			
187	E	Contacts mailing address			
188	E	Contact's email address			
<b>HOUSEHOLD INFORMATION</b>					
189	E	Household income (year before infant born)	<5,000 / 5,000-9,999 / 10,000-19,999 / 20,000-29,999 / 30,000-39,999 / 40,000-49,999 / 50,000 or more / 2002 POVERTY GUIDELINES-11,940 FOR 2 PERSONS, 15020 FOR 3, 18100 FOR 4, 21180 FOR 5; 24260 FOR 6; 27340 FOR 7; 30420 FOR 8 PERSONS;		
190	E	Is this a migrant family? Yes/No			
191	E	Number of children at home			
192	E	Number of adults at home			
193	E	Language spoken at home	English / Spanish / Other (specify)		

**Basic  
Information about  
CHILD**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (unique identifier)			
194	E	Birth certificate number			
195	E	Metabolic screening (blood spot) number			
196	E	Social security number (child)			
197	C	Last name (family name)			
198	C	First name (given name)			
199	C	Middle name (given name)			
200	M	Sex	Male / Female		
201	M	Ethnicity	Hispanic/Latino or not Hispanic		EHDI 1.3
202	M	Race	American Indian or Alaska Native/ Asian/ Black or African American; Native Hawaiian or Other Pacific Islander; White		EHDI 1.3
203	M	Mother (identifier)			
204	E	Father (identifier)			
166	C	Guardian's unique identifier			
205	E	Foster home (identifier)			
206	M	Date of birth (birth certificate)			EHDI 6.5; DSHPSHWA 3
207	C	Place of birth (city, county, state)			

**Information about  
CHILD'S RISK FACTORS**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (unique identifier)			EHDI 6.6
208	M	Family history of childhood permanent hearing loss?			EHDI 6.6, JCIH-1c, JCIH-2b.
209	M	In-utero (congenital) infections?	Yes/No		EHDI 6.6
210	M	In-utero (congenital) infection: Cytomegalovirus?	Yes/No		EHDI 6.6, JCIH-1e, JCIH-2e.
211	M	In-utero (congenital) infection: Rubella?	Yes/No		EHDI 6.6, JCIH-1e, JCIH-2e.
212	M	In-utero (congenital) infection: Syphilis (although not specifically mentioned?)	Yes/No		EHDI 6.6, JCIH-1e, JCIH-2e.
213	M	In-utero (congenital) infection: Herpes?	Yes/No		EHDI 6.6, JCIH-1e, JCIH-2e.
214	M	In-utero (congenital) infection: Toxoplasmosis?	Yes/No		EHDI 6.6, JCIH-1e, JCIH-2e.
215	M	In-utero (congenital) infection: Other?	Yes/No	(specify)	EHDI 6.6, JCIH-1e, JCIH-2e.
216	C	Low birth weight?	Yes/No	(specify birth weight)	EHDI 6.6
217	C	Low birth weight: Less than 1,500 grams	Yes/No		EHDI 6.6
218	C	APGAR score (0-4@1min or 0-6@5min)?	Yes/No		EHDI 6.6

**Information about  
CHILD'S RISK FACTORS(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
219	M	Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal.			EHDI 6.6 (JCIH-1d)
220	C	Defects of the head or neck region (e.g., cleft palate, ear tags, craniofacial abnormalities, malformed eyes, abnormal external ear canal)?			
221	C	Malformation of head or neck: Other (specify)?			
222	M	Findings associated with a syndrome known to include hearing loss?	Trisomy 21 / Pierre Robin syndrome / choanal atresia / Rubinstein-Taybi syndrome / Stickler syndrome / oculo-auriculo-vertebral (OAV) spectrum (Goldenbar syndrome) / Other (specify)		EHDI 6.6, JCIH-1b.
223	M	Admitted to NICU?	Yes / No		EHDI 6.6, JCIH-1a.
224	M	Days in NICU	Number of days	48 hours or more is a risk factor. Some data systems may collect risk factors (48 hours or more and more than 28 days) rather than number of days. Number of days was selected to allow for research-based changes in risk factor identification.	EHDI 6.6, JCIH-1a.

**Information about  
CHILD'S RISK FACTORS(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
225	C	Admission to NICU less than 48 hours		See items 228 and 229 for Minimum items	
226	C	Admission to NICU: 48 hours to 28 days?		See items 228 and 229 for Minimum items	
227	C	Neonatal indicators	Yes/No		
228	M	Neonatal indicators: hyperbilirubinemia requiring exchange transfusion	Yes/No		EHDI 6.6, JCIH-2f.
229	C	Neurodegenerative disorder?	Yes/No		EHDI 6.6
230	C	Ototoxic drugs?	Yes/No	Need to list which drugs	EHDI 6.6
231	C	Mechanical ventilation of 5+ days?	Yes/No		EHDI 6.6
232	C	Bronchio-pulmonary dysplasia?	Yes/No	ICD?	EHDI 6.6
233	M	Neonatal indicators: persistent pulmonary hypertension associated with mechanical ventilation	Yes/No		JCIH-2f.
234	M	Neonatal indicators: conditions requiring the use of ECMO	Yes/No		EHDI 6.6, JCIH-2f.
235	C	Other risk factors at natal hospital discharge?	Yes/No		EHDI 6.6
236	M	Parent or caregiver concern regarding hearing, speech, language, developmental delay or other?	Yes/No		JCIH-2a.

**Information about  
CHILD'S RISK FACTORS(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
237	M	Stigmata or other findings with SNHL or conductive HL or Eustachian tube dysfunction?	(specify)		JCIH-2c.
238	M	Postnatal infection: Bacterial meningitis?	Yes/No		JCIH-2d.
239	M	Postnatal infection associated with hearing loss: other?	(specify)		JCIH-2d.
240	M	Syndromes associated with progressive hearing loss	Neurofibromatosis / Osteopetrosis / Usher Syndrome / Other (specify)		JCIH-2g.
241	M	Neurodegenerative disorders or sensory motor neuropathies	Hunter Syndrome / Friedreich's Ataxia / Charcot-Marie-Tooth Syndrome / Other (specify)		JCIH-2h.
242	M	Head trauma?	Yes/No		JCIH-2i.
243	M	Recurrent or persistent otitis media with effusion (OME) for at least 3 months?	Yes/No		JCIH-2j.
244	E	Other risk factors identified after post-natal hospital discharge?  (DESCRIPTION OF RISK FACTORS)	Yes/No		
245	C	Description of syndromes and stigmata		Descriptive information on risk factors may be available through birth defects reporting or other sources.	

**Information about  
CHILD'S RISK FACTORS(continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
246	C	Description of neurologic disorders		See note for item 245.	
247	C	Description of infections		See note for item 245.	
248	C	Description of parental concerns		See note for item 245.	
249	C	Description of other risk factors		See note for item 245.	

**Information about  
CHILD'S BIRTH HOSPITALIZATION**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (identifier)			
1	M	Hospital or birthing facility (identifier)			EHDI 1.1; DSHPSHWA 10, 11, 13
250		Hospital medical record number for mother			
251		Hospital medical record number for child			
252		Hospital admission date for mother			
253		Hospital admission date for child		Used only if newborn hospitalized for reason other than birth.	
254	M	Date of birth (hospital record)			EHDI 1.1; DSHPSHWA 4–9a
255		Time of birth			

**Information about  
CHILD'S BIRTH HOSPITALIZATION (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
256		Cohort grouping based on date of birth	(User-defined list)		
257		Type of delivery	Vaginal / Forceps / C-Section / Vacuum extraction / Unknown		
258		Multiple birth (twin, triplet, etc.)			
259		Birth order (if multiple birth)			
260		Gestation age (estimated, weeks)	20 to 43		
261	E	Birth weight (grams)			
262	E	APGAR scores: 1 minute			
263	E	APGAR score: 5 minutes			
264	E	Nursery type	(User-defined list)		
265	C	Discharge type (discharged, transferred, died)			
266	M	Discharge date			EHDI 1.1; DSHPHWA 4a, 4b
267	C	Hospital or health facility if transferred (identifier)			
268	M	Insurance / payment type for birth hospitalization	Medicaid / Medicaid-HMO / Private insurance / Private HMO / Self-Pay	May not be available on birth certificate.	EHDI 1.3
269	E	Insurance / payment type for outpatient pediatric care	Medicaid / Medicaid-HMO / Private insurance / Private HMO / Self-Pay		

**Information about  
CHILD'S BIRTH HOSPITALIZATION (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
270	E	Primary care outpatient (child) - Pediatrician (identifier)			
271	E	Primary care outpatient (child) - Health facility (identifier)			
272	E	Primary family contact after discharge (identifier)			
273	E	Alternate family contact after discharge (identifier)			
274	E	Child will be living with	Mother / Father / Foster / Adoptive / Both / Other / Unknown		
275	E	Child's primary residence address after discharge			
276	E	Child's county of residence after discharge			

**Information about  
SCREENING (FIRST OR RE-SCREEN) TEST performed on child**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
277	M	Date of test			EHDI 6.5; DSHPSHWA 4a, 4b, 5
126	M	Child tested (identifier)			
278	E	Chronological age	test date - birth date		
279	E	Corrected age	test date - (birth date + (40 - gestation age))		

**Information about  
SCREENING (FIRST OR RE-SCREEN) TEST performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
280	C	First screen or re-screen?		State system may not maintain information on each screening and diagnostic event.	
281	M	Facility (identifier)			EHDI 1.1
282	C	Person (screeener) performing screening test (identifier)			
283	E	Inpatient or outpatient?  Risk factors for hearing loss		See section on risk factors.	
284	M	Right ear: Equipment type (e.g. DPOAE, TEOAE, ABR)	OAE / ABR or more detailed codes?		EHDI 6.6
285	E	Right ear: Equipment used			
286	M	Right ear: Test completed successfully?	Yes/No		EHDI 6.9; DSHPSHWA 4, 4a, 4b, 5
287	M	Right ear: Test completion code	(Completed) / Could not test / Invalid / Missed / Refused / Transferred / Scheduled / Broken appointment / Deceased / Follow-up discontinued		EHDI 1.1, 6.5, 6.9
288	M	Right ear: Test results (e.g. pass/refer)	Pass / Refer / NA		EHDI 6.9; DSHPSHWA 5, 7a, 13
289	M	Left ear: Equipment type (e.g. DPOAE, TEOAE, ABR)	OAE / ABR or more detailed codes?		EHDI 6.6
290	E	Left ear: Equipment used			
291	M	Left ear: Test completed successfully?	Yes/No		EHDI 6.9; DSHPSHWA 4, 4a, 4b, 5

**Information about  
SCREENING (FIRST OR RE-SCREEN) TEST performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
292	M	Left ear: Test completion code	Same as Right ear		EHDI 1.1, 6.5, 6.9
293	M	Left ear: Test results (e.g. pass/refer)	Pass / Refer / NA	Pass / Refer / Not tested	EHDI 6.9; DSHPSHWA 5, 7a, 13
294	M	Disposition (e.g. re-screen, refer for evaluation)			EHDI 6.9; DSHPSHWA 5, 11
295	E	UNHS coordinator notified?			
296	E	Appointment facility (identifier)		Looking at next stage if no record, manual follow-up	
297	E	Appointment date and time			
298	E	Comments about hearing screening procedure			
299	E	Comments about child or family			
300	E	Insurance / payment type (public, private, self) Public / private / self-pay			
301	E	Insurance carrier reimbursement			
302	E	Cumulative time spent in screening (minutes).			
303	E	Number of attempts			

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
254	C	Date of birth		Can be carried forward from other records. Same as Item # 210	
1	C	Birthplace (Birthing Hospital or Facility ID)		Can be carried forward from other records.	
	C	Health information		Need to specify. Can be carried forward from other records.	
311	C	Risk factors for hearing loss (see section on risk factors)		Need to specify. Can be carried forward from other records.	
	C	Previous screening data		Need to specify. Can be carried forward from other records.	
303	M	Date of evaluation			EHDI 6.10; DSHPSHWA 6, 6a, 8
126	M	Child tested (unique identifier)			EHDI 6.10; DSHPSHWA 6, 6a, 8
304	E	Chronological age	(Not calculated now)		
305	E	Corrected age	(Not calculated now)		
306	C	Reason for evaluation	Repeat screening / evaluation		
307	C	Diagnostic Facility (identifier)			
308	C	Is tester an Audiologist?	Yes/No		
309	E	Person performing evaluation (identifier)			
310	E	Inpatient or outpatient?			

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
311	C	Risk factors for hearing loss		See section on risk factors. Add new (previously missing) or changed information.	
312	E	Parental concern regarding hearing status-	Yes / No / Unk Add new (previously missing) or changed information.		
313	C	Family history of hearing loss (blood relatives)?	Parents / sibs / grandparents / aunts / uncles / first cousins	Add new (previously missing) or changed information.	
314	C	Results of prior diagnostic testing			
315	E	Infant has hearing aid(s)?	Yes / No / Unknown		
316		Congested today?	Yes / No / Unknown		
317	E	Ear infections?			
318	E	Ear infections: Number of infections to date			
319	E	Ear infections: Infection within last month?	Yes / No / Unknown		
320	E	Ear infections: Ear tubes at time of this test?	Yes / No / Unknown		
321	E	Illness, conditions or treatments since screening possible affecting hearing or neurological status?	Herpes / meningitis / pertussis / mumps / sepsis / tuberculosis / hypoxia / seizures / hydrocephalus / head trauma / chemotherapy / radiation therapy / kidney failure / cystic fibrosis / mechanical ventilation / ECMO / cardiac surgery / neurological illness / neurological surgery / newly diagnosed syndrome / Other		
322	E	Describe illness, condition of treatments			

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
323	C	Right ear: Physical examination			
324	C	Right ear: Physiologic test performed	DPOAE / TEOAE / ABR click or frequency specific		
325	C	Right ear: Behavioral tests performed	VOA / VRA / other (specify)		
326		Right ear: Equipment used			
327	E	Right ear: Equipment manufacturer/model			
328	C	Right ear: Sound field used			
329	C	Right ear: Evaluation completed successfully?			
330	M	Right ear: Evaluation completion code	(Completed) / Broken appointment / Could not test / Deceased / Invalid / Lost / Missed / No response / Refused / Scheduled / Transferred		EHDI 6.10; DSHPSHWA 6, 6a
331	C	Right ear: Evaluation result: TEOAE or DPOAE	Normal / Abnormal / Could not do/ Did not do		
332	C	Right ear: Evaluation result: Tympanometry 226 Hz	Normal / Abnormal / Could not do/ Did not do		
333	C	Right ear: Evaluation result: Tympanometry - Other frequencies (specify)	Normal / Abnormal / Could not do/ Did not do		
334	C	Right ear: Evaluation result: ABR Click Threshold		dBnHL	

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
335	C	Right ear: Evaluation result: ABR Toneburst Threshold 500Hz		dBnHL	
336	C	Right ear: Evaluation result: ABR Toneburst Threshold 1000Hz		dBnHL	
337	C	Right ear: Evaluation result: ABR Toneburst Threshold 2000Hz		dBnHL	
338	C	Right ear: Evaluation result: ABR Toneburst Threshold 4000Hz		dBnHL	
339	C	Right ear: Evaluation result: Behavioral tests			
340	M	Right ear: Diagnosis: Hearing loss?	PCHL?		EHDI 6.13; DSHPSHW 7, 7a, 9, 15
341	M	Right ear: Diagnosis: Degree of hearing loss	Mild (<=40db) / Moderate (41-60db) / Severe (61-80db) / Profound (>80db)		DSHPSHW 15
342	M	Right ear: Diagnosis: Type of hearing loss	Fluctuating conductive / Permanent conductive / Sensorineural / Mixed / Unspecified		DSHPSHW 15
343	C	Left ear: Physical examination			
344	C	Left ear: Physiologic test performed	DPOAE / TEOAE / ABR click or frequency specific		
345	C	left ear: Behavioral tests performed	VOA / VRA / other (specify)		
346		Left ear: Equipment used			
347	E	left ear: Equipment manufacturer/model			
348	C	left ear: Sound field used			

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
348	C	left ear: Evaluation completed successfully?			
349	M	Left ear: Evaluation completion code	(Completed) / Broken appointment / Could not test / Deceased / Invalid / Lost / Missed / No response / Refused / Scheduled / Transferred		EHDI 6.10; DSHPSHWA 6, 6a
350	C	Left ear: Evaluation result: TEOAE or DPOAE	Normal / Abnormal / Could not do/ Did not do		
351	C	Left ear: Evaluation result: Tympanometry 226 Hz	Normal / Abnormal / Could not do/ Did not do		
352	C	Left ear: Evaluation result: Tympanometry - Other frequencies (specify)	Normal / Abnormal / Could not do/ Did not do		
353	C	Left ear: Evaluation result: ABR Click Threshold		dBnHL	
354	C	Left ear: Evaluation result: ABR Toneburst Threshold 500Hz		dBnHL	
355	C	Left ear: Evaluation result: ABR Toneburst Threshold 1000Hz		dBnHL	
356	C	Left ear: Evaluation result: ABR Toneburst Threshold 2000Hz		dBnHL	
357	C	Left ear: Evaluation result: ABR Toneburst Threshold 4000Hz		dBnHL	
358	C	Left ear: Evaluation result: Behavioral tests			
359	M	Left ear: Diagnosis: Hearing loss?	PCHL?		EHDI 6.13; DSHPSHWA 7, 7a, 9, 15

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
360	M	Left ear: Diagnosis: Degree of hearing loss	Mild ( $\leq 40$ db) / Moderate (41-60db) / Severe (61-80db) / Profound ( $> 80$ db)		DSHPSHWA 15
361	M	Left ear: Diagnosis: Type of hearing loss	Fluctuating conductive / Permanent conductive / Sensorineural / Mixed / Unspecified		DSHPSHWA 15
362	C	Disposition Further evaluation (referred / kept in) / Early Intervention / ENT / Neurologist / Physician / Audiologist / Discharge	Add lost to follow-up? Audiologist recommends to primary care provider and provider makes referral.		
363	C	Referred for further evaluation?	Recommended / referred		
364	E	Type of/Reason for referral			
365	C	Referral to: Facility (identifier)			
366	C	Referral to: Provider (identifier)			
367	C	Referral to: Appointment date and time			
368	C	Referred for early intervention?			
369	C	Referral to: Early intervention program (identifier)			
370	C	Referral to: EI Facility (identifier)			
371	C	Referral to: EI Provider (identifier)			

**Information about  
DIAGNOSTIC HEARING EVALUATION performed on child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
372	C	Referral to: Appointment date and time			
373	C	Referral to: Medical Evaluation			
374	C	Referral to: Genetics			
375	E	Recommendation to primary care provider			
376	C	Insurance / payment type	self-pay, provider pay, public pay		
377	E	Visit reimbursed?			
378	E	Comments about hearing evaluation procedure			
379	E	Comments about child or family			
380	E	Test start and end times			
381	E	Cumulative time spent in evaluation (minutes)			
382	E	Is diagnosing audiologist the fitting audiologist?			
383	E	Date the hearing aid was fit			

**Information about  
EARLY INTERVENTION SERVICES  
received by each child with HEARING LOSS**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (identifier)			
370	C	Facility (identifier)			
384	C	Program (identifier)			
371	C	Provider (identifier)			

**Information about  
EARLY INTERVENTION SERVICES  
received by each child with HEARING LOSS (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
385	M	Intervention service start date			DSHPHWA 9, 9a
386	C	Intervention service end date			
387	M	Individualized family service plan (IFSP) for child?			EHDI 6.13
388	C	IFSP date			
389	E	Birth to 3 enrollment	YES/NO		
390	E	Audiologic services to child?	Hearing monitoring, auditory training, hearing aid fitting (which ear?), hearing aid monitoring, FM fitting (ear?), FM monitoring, other	More than one service possible	
391	E	Speech-language services to child?	Auditory, vocal-verbal, signing English, American Sign Language, Bilingual-bicultural, cued speech, other	More than one service possible	
392	E	Speech-language services to child: Communication method / language learning approach used			
393	E	Speech-language services to child: Language inventory used			
394	E	Speech-language services to child: Receptive language level			

**Information about  
EARLY INTERVENTION SERVICES  
received by each child with HEARING LOSS (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
395	E	Language-language services to child: Expressive language level			
396	C	Type of service	Amplification, audiology, child/child group, home visits, medical ophthalmology, genetics, neurology, nursing, parent-infant group, parent-parent group, parent-toddler group, parent education, service coordination, speech or language, community outreach, referral, other	Need to refine type of service list; type will differ by category of service; need agreement on categories and types within category. Each child may have several categories of service and several types of service and/or types of providers within each category.	
397	C	Type of provider	Primary care provider, specialty physician, audiologist, physician's assistant, nurse practitioner, nurse, health educator, paraprofessional		
398	C	Category of service  Description of each service			
399	E	Provided education materials and community resources guide to parents?	Yes / No		
400	E	CSHCN coordinator notified?	Yes / No		
401	E	Insurance / payment type public private, self-pay			
402	E	Is payer reimbursed?	Payer name		
403	E	Comments			

**Information about  
MEDICAL EVALUATION AND MEDICAL INTERVENTION  
received by each child with HEARING LOSS**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (identifier)			
404	C	Facility (identifier)			
405	C	Program (identifier)			
406	C	Provider (identifier)			
407	C	Date of evaluation or intervention			
408	C	Physical examination	Yes/No		
409	C	Primary Diagnoses: Dymorphology codes, diagnostic ICD codes	386 series ICD codes		
410	C	Medical treatment	Cochlear implant / other	Need to identify treatments	
411	C	Other early intervention services provided		See section on Intervention Services	
412	C	Referrals			
413	C	Genetic information, counseling, or referral	Genetic tests performed / counseling / info provided / referral made / not discussed		
414	C	Insurance/payment type	Public / private / self		
415	E	Additional/new JCIH risk factors identified?	Yes/No	See Risk Factor pages	
416	E	Corollary conditions?	Yes/No		
417	E	Comments			

**Information about  
GENETIC TESTING of each child with HEARING LOSS and  
GENETIC COUNSELING for families**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
126	M	Child (identifier)			
418	C	Facility (identifier)		May be same as item 43.	
419	C	Program (identifier)			
420	C	Provider (identifier)		May be same as item 114.	
421	C	Dates of tests			
422	C	Genetic tests performed	Yes/No		
423	C	Laboratory performing test (identifier)		May be same as item 69.	
424	C	Genetic tests results (specific tests)			
425	C	Genetic counseling provided for parents?	Yes/No		
426	C	Hearing loss appears to be syndromic?	Yes/No	Do we need a field for type of syndromic hearing loss?	
427	C	Insurance/payment type	Public / private / self		
428	E	Comments			

**Information about  
SPEECH AND LANGUAGE DEVELOPMENT  
of each CHILD with HEARING LOSS**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
26	M	Child (identifier)			
429	C	Facility (identifier)			
430	C	Speech and Language Development Program (identifier)			
431	C	Provider (identifier)			
432	C	Dates of evaluation report			

## Types of COMMUNICATIONS TO PARENTS AND PROVIDERS

Item #	Data Need	Data item description	Categories or codes	Notes	Measure Component
126	M	Child (identifier)			
433	E	Type of communication (phone / letter / email / data transfer)	(Printed letter only)		
434	E	Date of communication			
435	E	From whom			
436	E	To whom	(Mother) / (Physician)		
437	E	Subject	Initial screening pass / Initial refer for rescreen / Initial refusal / Initial inconclusive or missed / Initial or rescreen broken appointment / Locate or contact attempt / Rescreen pass / Rescreen refusal / Referral for DxABR / Refer for behavioral / Risk indicator monitoring		
438	E	Message	(Boilerplate mail merge)		

**Summary report of STATUS of  
SCREENING, EVALUATION, HEARING LOSS and  
INTERVENTION of child**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
303	345/ 364	Hearing loss confirmed? (date)	Yes / No		
362	347/ 366, 346/ 365, 367	Type and degree of hearing loss (L/R ears, sound field)			
308		Is tester an Audiologist	Yes/No		
309		Person performing evaluation (identifier)			
439		Amplification type			
383		Date of hearing aid fitting			
440		Child's age (months) at time of hearing aid fitting			
441		Referral for tracking assistance			
362		Case referred to early intervention			
371		EI Caseworker			
385		Early interventions (type and dates)	Amplification / Audiology / Child-child group / Home visits / Medical / Nursing / Parent-infant group / Parent-parent group / Parent-toddler group / Parent education / Service coordination / Speech or language		
442		Hearing assessment audiologist's recommendations	Diagnostic ABR / Behavioral / Medical follow-up / Risk monitoring / Locate or lost / Follow-up discontinued		

**Summary report of STATUS of  
SCREENING, EVALUATION, HEARING LOSS and  
INTERVENTION of child (continued)**

<b>Item #</b>	<b>Data Need</b>	<b>Data item description</b>	<b>Categories or codes</b>	<b>Notes</b>	<b>Measure Component</b>
443		Recommendation date			
444		Action Due date			
		(PARENT EDUCATION)			
		(MEDICAL EVALUATION AND INTERVENTIONS)			
		(GENETIC TESTING AND COUNSELING)			
		(EARLY INTERVENTIONS)			
		(SPEECH AND LANGUAGE DEVELOPMENT)			



## APPENDIX IV

APPENDIX IV  
Annual Statistical Report Worksheet

Adapted from the National ELDI Goals and Objectives (July, 2002)

State: _____
Contact Name: _____
Contact Phone Number: _____
Contact Email Address: _____
Date Completed: _____

Reporting Year:

\_\_\_\_\_

For each performance indicator below, report the number and percentage to the right. Remember to only include data for the selected reporting year.

**Goal 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.**

Performance Indicator 1.1	Number	Percent
a. What number/percent of birthing hospitals in the state screened at least 90% of infants before discharge?		
b. What number/percent of small hospitals do not screen but have plans for referral of infants to a screening program, including designation of responsible staff position(s) and timeline?		
c. What number/percent of infants were screened before hospital discharge?		
d. What number/percent of infants were screened before 1 month of age?		
e. What number/percent of families refused screening?		
Performance Indicator 1.3	Number	Percent
a. What number/percent of the state's live births are:		
a1. White?		
a2. Black or African American?		
a3. Asian?		
a4. American Indian or Alaskan Native?		
a5. Native Hawaiian or Pacific Islander?		

D. What number/percent of the mothers of the state's newborns have:		
b1. Less than a high school education?		
b2. A high school diploma/GED?		
b3. Some college?		
b4. A college degree?		
b5. Some graduate school?		
b6. A graduate degree?		
c. What number/percent of the mothers of the state's newborns are covered by:		
c1. Medicaid?		
c2. Medicaid-HMO?		
c3. Private insurance?		
c4. Private HMO?		
c5. Self-pay?		
<b>Performance Indicator 1.4</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of infants were born out of hospital?		
b. What number/percent of infants born out of hospital received a hearing screening before one month of age?		
<b>Performance Indicator 1.7</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of infants who did not pass the initial inpatient or outpatient screening were referred for diagnostic evaluation?		

**Goal 2.** All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.

<b>Performance Indicator 2.1</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of infants who screened positive received a comprehensive audiologic evaluation before 3 months of age?		
b1. What number/percent of infants were diagnosed with bilateral HL?		
b2. What number/percent of infants were diagnosed with unilateral HL?		
c1. What number/percent of infants were diagnosed with permanent conductive HL?		

c2. What number/percent of infants were diagnosed with sensorineural HL?		
c3. What number/percent of infants were diagnosed with auditory dys-synchronous HL?		
d1. What number/percent of infants were diagnosed with mild HL?		
d2. What number/percent of infants were diagnosed with moderate HL?		
d3. What number/percent of infants were diagnosed with severe HL?		
d4. What number/percent of infants were diagnosed with moderately-severe HL?		
d5. What number/percent of infants were diagnosed with profound HL?		
e. What number/percent of infants referred for audiologic evaluation were lost to follow-up?		
f. What number/percent of infants at risk of developing late onset HL were lost to follow-up?		
g. What number/percent of infants referred for audiologic evaluations were not screened for HL?		
<b>Performance Indicator 2.3</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of centers and audiologists (total) have appropriate equipment to conduct diagnostic evaluation of infants?		
b. How many hospitals or referral personnel maintain a list of diagnostic centers or audiologists?		
<b>Performance Indicator 2.4</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of infants identified with HL were referred to medical specialists (e.g., otolaryngologists, ophthalmologists, geneticists)?		
b. What number/percent of infants with HL were referred to early intervention services (including counseling and support services)?		
c. What number/percent of infants with HL were referred for ongoing audiologic evaluations and services?		

**Goal 3.** All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

Performance Indicator 3.1	Number	Percent
a1. What number/percent of infants with HL received any medical services before 6 months of age?		
a2. What number/percent of infants with HL received medical services before 6 months of age from primary care providers?		
a3. What number/percent of infants with HL received medical services before 6 months of age from otolaryngologists?		
a4. What number/percent of infants with HL received medical services before 6 months of age from ophthalmologists?		
a5. What number/percent of infants with HL received medical services before 6 months of age from geneticists/genetic counselors?		
Performance Indicator 3.2	Number	Percent
a. What number/percent of infants with HL were enrolled in an intervention program before 6 months of age?		
b. What number/percent of infants and children with HL received family support information about early intervention services?		
c1. What number/percent of eligible infants and children with mild HL have a signed IFSP or an equivalent intervention plan?		
c2. What number/percent of eligible infants and children with moderate HL have a signed IFSP or an equivalent intervention plan?		
c3. What number/percent of eligible infants and children with severe HL have a signed IFSP or an equivalent intervention plan?		
c4. What number/percent of eligible infants and children with moderately severe HL have a signed IFSP or an equivalent intervention plan?		
c5. What number/percent of eligible infants and children with profound HL have a signed IFSP or an equivalent intervention plan?		
d. What number/percent of infants were lost to follow-up after identification?		
e1. What number/percent of infants with mild HL were eligible for Part C services?		
e2. What number/percent of infants with moderate HL were eligible for Part C services?		
e3. What number/percent of infants with severe HL were eligible for Part C services?		
e4. What number/percent of infants with moderately severe HL were eligible for Part C services?		

e5. What number/percent of infants with profound HL were eligible for Part C services?		
<b>Performance Indicator 3.3</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of infants with HL were fitted with personal amplification before 6 months of age?		
<b>Performance Indicator 3.5</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of parents and guardians of infants with confirmed HL (that reached 6 months of age within the last calendar year) received a copy of the state resource guide?		
<b>Performance Indicator 3.6</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of intervention teams include individuals with professional preparation and experience working with children with HL?		
<b>Performance Indicator 3.9</b>	<b>Number</b>	<b>Percent</b>
a1. What number/percent of families were referred to parent-to-parent support programs?		
a2. What number/percent of families who were referred to parent-to-parent support programs are currently involved in a program?		
<b>Performance Indicator 3.10</b>	<b>Number</b>	<b>Percent</b>
a. What number/percent of parents are involved in their child's program planning, evaluation, or monitoring?		
b. How many/what percent of the advisory members are parents?		

**Goal 4.** All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.

Performance Indicator 4.1	Number	Percent
a. What number/percent of infants had one or more risk factor?		
Performance Indicator 4.2	Number	Percent
a. What number/percent of infants with risk factors were rescreened by 6 months?		
Performance Indicator 4.3	Number	Percent
a. What number/percent of infants and children were identified with acquired hearing loss?		

**Goal 5.** All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.

Performance Indicator 5.1	Number	Percent
a. What number/percent of infant records included the name of the infant's primary care provider?		
Performance Indicator 5.4	Number	Percent
a. What number/percent of medical homes (including physicians, midwives, etc.) received written information and/or attended a session about the EHDI program?		
Performance Indicator 5.5	Number	Percent
a. What number/percent of parents participated in the development and evaluation of the medical home?		
Performance Indicator 5.6	Number	Percent
a. What number/percent of infant records included updated documentation of who the primary care provider was at birth, enrollment in early intervention and at each IFSP contact?		

**Goal 6.** Every state will have a complete EMDI tracking and surveillance system that will minimize loss to follow-up.

Performance Indicator 6.4	Number	Percent
a. How many live-born infants were born during the reporting year?		
b. What number/percent of infants in the birth certificate registry are also included in the EMDI system?		
Performance Indicator 6.5	Number	Percent
a. What number/percent of infants had risk factors for hearing loss?		
b. What number/percent of infants with risk factors fell into each risk factor group?		
b1. Risk Factor 1: _____		
b2. Risk Factor 2: _____		
b3. Risk Factor 3: _____		
Performance Indicator 6.7	Number	Percent
a. What number/percent of health care providers have protocols for reporting hearing screening results, evaluations and interventions?		
b. What number/percent of health care providers reported hearing screening results to the state?		
Performance Indicator 6.8	Number	Percent
a1. What number/percent of infants and children needed follow-up who were referred for a second screening?		
a2. What number/percent of infants and children needed follow-up who missed a screening?		
a3. What number/percent of infants and children needed follow-up who needed a repeat screening?		
a4. What number/percent of infants and children needed follow-up who were referred for diagnosis?		
a5. What number/percent of infants and children needed follow-up who were referred for early intervention?		
b. What number/percent of infants and children received follow-up services?		

**Goal 7.** Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDl Goals and Objectives.

Performance Indicator 7.4	Number	Percent
a. What number/percent of infants and children with hearing loss received appropriate ongoing medical services from primary care, otolaryngologists, pftalmologists, geneticists and genetic counselors?		
b1. How many infants and children were fit with implants?		
b2. What was the mean age of implantation?		
c. What number/percent of infants and children have selected each mode of communication?		
c1. Sign language?		
c2. Oral?		
c3. Cued speech?		
d. What number/percent of infants and children achieved communication and social skills scores commensurate with their cognitive abilities age at:		
d1. 1 year of age: _____		
d2. 3 years of age: _____		
d3. 5 years of age: _____		
d4. 7 years of age: _____		
e. What number/percent of infants and children with hearing aids received follow-up visits at 2-month intervals until age 2 years and 3-month intervals until age 3?		

## APPENDIX V

### EHDI Program Stakeholders

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The following is a list of potential persons and organizations that may have a strong interest or association with state EHDI programs. Persons and organizations that do have an interest and/or involvement with EHDI programs are classified as stakeholders. The following list of professionals, organizations, and federal and state agencies represents common stakeholders in EHDI programs.

Stakeholder information may be helpful in preparing and identifying audiences for an EHDI annual report. Additional stakeholders may need to be identified according to each state's specific needs and organizational structure.

Stakeholders have been organized into seven broad groups for this manual. The first group of stakeholders is consumers, which are populations in the state who are directly impacted by EHDI programs. The second and third groups are professionals outside the state Department of Health (DOH) or Department of Human Services who are involved in providing services. These services are divided up into the processes from screening through diagnostic evaluation and the delivery of intervention services once a diagnosis has been made. The fourth group consists of DOH staff and Department of Human Services. The fifth group consists of individuals from the public and private sector whose advice or decisions may affect access to and funding for EHDI related services. Sixth, we consider other groups that may have an interest in specific state programs and practices. Finally, we include all national-level EHDI stakeholders, including federal agencies, their contractors, advocacy groups, and professional associations. Many advocacy groups and professional agencies also have state affiliates who could be considered under the sixth category. To avoid repetition, each group is only listed once.

## Consumers

- Parents and families
- People who are deaf or hard of hearing

## External (non-DOH) groups involved with screening, follow-up and diagnosis

- Hospitals and their staff (i.e., screeners)
- Audiologists
- Nurses
- Primary health care providers
- Specialist physicians
- Genetic counselors

## Groups involved with intervention service

- Infant and Toddlers with Disabilities (IDEA, Part C)
- Area Schools for the Deaf
- Area education programs (i.e. teachers of people with hearing loss)
- State Department of Education (i.e., Special Education Programs)

## State health department programs and staff

- EHDI program
- Birth Defects branch, section or department
- Genetics branch or section of a DOH (if one exists)
- Newborn blood spot screening program
- State programs focusing on Children with Special Health Care Needs
- State programs with surveillance components (i.e. lead program)
- Vital records departments

## Advisory and decision makers

- State EHDI Advisory Boards
- Professional regulatory boards
- Department of Health (DOH) management
- State Medicaid agency
- State legislature
- Governor's office
- Medical insurers

## Other interested parties in state

- University programs offering courses/degree programs in Audiology, Speech-language pathology, deaf education, and Early intervention
- University affiliated programs working with permanent childhood hearing loss
- Border states

## National level stakeholders

### *Specific EHDI Focus:*

- CDC EHDI program
- HRSA/MCHB UNHSI
- Marion Downs National Center for Infant Hearing (MDNC)
- National Center for Hearing Assessment and Management (NCHAM)
- National Institutes of Health (NIH)
- The Office of Special Education and Rehabilitative Services (OSERS)
- Boys Town National Research Hospital
- Collaborative Early Intervention National Training e-Resource (CENTe-R)

### *Professional Organizations:*

- American Academy of Pediatrics (AAP)
- American Academy of Family Physicians (AAFP)
- American Academy of Otolaryngology- Head and Neck Surgery (AAO-HNS)
- American Academy of Audiology (AAA)
- American Speech-Language-Hearing Association (ASHA)
- Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA)

### *Constituent/Consumer Organizations (specific to serving individuals with hearing loss)*

- Alexander Graham Bell Association for the Deaf (AG Bell)
- American Society for Deaf Children (ASDC)
- Auditory Verbal International (AVI)
- Cued Speech
- National Association for the Deaf (NAD)
- Self Help for the Hard of Hearing (SHHH)

## APPENDIX VI

### Independent State EHDI Websites

Please note: This document is not a complete list of state EHDI websites and it is continually being updated. If you have any comments please contact the EHDI program: [ehdi@cdc.gov](mailto:ehdi@cdc.gov)

State	Website
Alaska	<a href="http://health.hss.state.ak.us/dph/mcfh/child/default.htm">http://health.hss.state.ak.us/dph/mcfh/child/default.htm</a>
Arizona	<a href="http://www.earfoundationaz.com/page_010.html">http://www.earfoundationaz.com/page_010.html</a>
California	<a href="http://www.dhs.cahwnet.gov/pcfh/cms/HTML/NHSP.htm">http://www.dhs.cahwnet.gov/pcfh/cms/HTML/NHSP.htm</a>
Colorado	<a href="http://www.cdphe.state.co.us/ps/bestpractices/topicsubpages/newborn.asp">http://www.cdphe.state.co.us/ps/bestpractices/topicsubpages/newborn.asp</a>
Connecticut	<a href="http://www.dph.state.ct.us/BCH/Family%20Health/newborn/unhsp.htm">http://www.dph.state.ct.us/BCH/Family%20Health/newborn/unhsp.htm</a>
Florida	<a href="http://www.cms-kids.com/InfantHearing.htm">http://www.cms-kids.com/InfantHearing.htm</a>
Georgia	<a href="http://health.state.ga.us/programs/unhs/index.shtml">http://health.state.ga.us/programs/unhs/index.shtml</a>
Idaho	<a href="http://www2.state.id.us/cdhh/ehdi/">http://www2.state.id.us/cdhh/ehdi/</a>
Illinois	<a href="http://www.state.il.us/agency/dhs/4625nhsnp.html">http://www.state.il.us/agency/dhs/4625nhsnp.html</a>
Indiana	<a href="http://www.in.gov/isdh/programs/mch/newbornuniver.htm">http://www.in.gov/isdh/programs/mch/newbornuniver.htm</a>
Iowa	<a href="http://www.idph.state.ia.us/fch/newborn/default.htm">http://www.idph.state.ia.us/fch/newborn/default.htm</a>
Kansas	<a href="http://www.kdhe.state.ks.us/sb/index.html">http://www.kdhe.state.ks.us/sb/index.html</a>
Kentucky	<a href="http://commissionkids.state.ky.us/unhs.htm">http://commissionkids.state.ky.us/unhs.htm</a>
Louisiana	<a href="http://www.oph.dhh.state.la.us/childrensspecial/hearspeech/index.html">http://www.oph.dhh.state.la.us/childrensspecial/hearspeech/index.html</a>
Maryland	<a href="http://www.fha.state.md.us/genetics/html/inf_hrg.html">http://www.fha.state.md.us/genetics/html/inf_hrg.html</a>
Massachusetts	<a href="http://www.state.ma.us/DPH/bfch/shn/early/unhsp.htm">http://www.state.ma.us/DPH/bfch/shn/early/unhsp.htm</a>
Michigan	<a href="http://madhs.us.net/">http://madhs.us.net/</a>
Minnesota	<a href="http://www.health.state.mn.us/divs/fh/mch/unhs">http://www.health.state.mn.us/divs/fh/mch/unhs</a>
Mississippi	<a href="http://www.msdh.state.ms.us/ophs/EARLYINT/new.htm">http://www.msdh.state.ms.us/ophs/EARLYINT/new.htm</a>
Montana	<a href="http://www.msubillings.edu/unhs/what_is.htm">http://www.msubillings.edu/unhs/what_is.htm</a>
Nevada	<a href="http://communitylink.koz.com/servlet/Ivrj_ProcServ/DBPAGE=cge&amp;GID=01010010550956010802599134">http://communitylink.koz.com/servlet/Ivrj_ProcServ/DBPAGE=cge&amp;GID=01010010550956010802599134</a>
New Jersey	<a href="http://www.state.nj.us/health/fhs/scnbhrg.htm">http://www.state.nj.us/health/fhs/scnbhrg.htm</a>

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<b>State</b>	<b>Website</b>
North Carolina	<a href="http://www.ncnewbornhearing.org/">http://www.ncnewbornhearing.org/</a>
North Dakota	<a href="http://www.ndcd.org/1stsounds/">http://www.ndcd.org/1stsounds/</a>
Ohio	<a href="http://www.odh.state.oh.us/ODHPrograms/HEAR_INF/hearinf1.htm">http://www.odh.state.oh.us/ODHPrograms/HEAR_INF/hearinf1.htm</a>
Oklahoma	<a href="http://www.health.state.ok.us/program/sss/index.html">http://www.health.state.ok.us/program/sss/index.html</a>
Oregon	<a href="http://www.ohd.hr.state.or.us/pcah/hearing/welcome.htm">http://www.ohd.hr.state.or.us/pcah/hearing/welcome.htm</a>
Pennsylvania	<a href="http://www.psha.org/newborn_hearing.htm">http://www.psha.org/newborn_hearing.htm</a>
Rhode Island	<a href="http://www.healthri.org/family/hearing/home.htm">http://www.healthri.org/family/hearing/home.htm</a>
South Carolina	<a href="http://www.scdhec.net/HS/mch/cshcn/cshcnprograms.htm">http://www.scdhec.net/HS/mch/cshcn/cshcnprograms.htm</a>
South Dakota	<a href="http://www.state.sd.us/doh/famhlth/nhprogram.htm">http://www.state.sd.us/doh/famhlth/nhprogram.htm</a>
Tennessee	<a href="http://www2.state.tn.us/health/FactSheets/hearing.htm">http://www2.state.tn.us/health/FactSheets/hearing.htm</a>
Texas	<a href="http://www.tdh.state.tx.us/audio/audiology.htm">http://www.tdh.state.tx.us/audio/audiology.htm</a>
Utah	<a href="http://health.utah.gov/cshcn/hsvs/">http://health.utah.gov/cshcn/hsvs/</a>
Vermont	<a href="http://www.healthyvermonters.info/hi/cshn/hearing/hcprograms.shtml">http://www.healthyvermonters.info/hi/cshn/hearing/hcprograms.shtml</a>
Virginia	<a href="http://www.vahealth.org/hearing/">http://www.vahealth.org/hearing/</a>
Washington	<a href="http://www.doh.wa.gov/cfh/mch/Geneticshome.htm">http://www.doh.wa.gov/cfh/mch/Geneticshome.htm</a>
Wisconsin	<a href="http://www.perinatalweb.org/association/unhs.html">http://www.perinatalweb.org/association/unhs.html</a>
Wyoming	<a href="http://wind.uwyo.edu/wind/research/earlyinfo.htm">http://wind.uwyo.edu/wind/research/earlyinfo.htm</a>

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## APPENDIX VII

### RESOURCES

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\*Alexander Graham Bell Association for the Deaf is a nonprofit membership organization designed to help people who are hearing impaired to function independently. AGBell promotes universal rights and provides opportunities to learn to use, maintain, and improve all aspects of verbal communications. This Web site has information on publications and locations of their state chapters. <http://www.agbell.org/>

\*American Academy of Audiology is a professional organization dedicated to providing quality hearing care to the public. This Web site provides consumer and professional resources related to hearing care. <http://www.audiology.org/>

\*American Academy of Otolaryngology-Head and Neck Surgery is the world's largest organization of physicians dedicated to the care of ear, nose, and throat disorders. This site provides health tips and information related to hearing disorders. <http://www.entnet.org/>

\*American Academy of Pediatrics This web site contains information, alerts, and resources related to the physical, mental, and social health of infants, children, adolescents, and young adults. Pediatrics is an online publication of the American Academy of Pediatrics journal. The following is an article from one of their publications: Universal Newborn Hearing Screenings: A Three Year Experience. <http://www.aap.org/> <http://www.pediatrics.org/>

\*American Society for Deaf Children is an organization of parents and families that advocates for deaf or hard of hearing children's total quality participation in education, the family and the community. This site provides information and resources to families and parents related to hearing loss. <http://www.deafchildren.org/>

\*American Speech-Language-Hearing Association (ASHA) Newborn & Infant Hearing Screening Action Center provides information on newborn hearing screening guidelines and current legislation. <http://www.asha.org/>

\*American Academy of Family Physicians is a national, non-profit medical association of more than 88,000 members (family physicians, family practice residents, and medical students). This Web site provides information to professionals within the medical field. <http://www.aafp.org/>

\*Auditory-Verbal International, Inc. is a private non-profit international membership organization whose goals are to heighten public awareness of the auditory-verbal approach, ensure certification standards for auditory-verbal clinicians and teachers, provide quality educational opportunities for parents and professionals, and facilitate networking among the professional and lay communities. <http://www.auditory-verbal.org/>

\*The Helen Beebe Center is recognized worldwide as one of the foremost professional auditory-verbal therapy centers for hearing impaired children and their families. <http://www.beebecenter.org/>

\*Better Hearing Institute provides comprehensive information on hearing loss, tinnitus, and hearing aids, as well as a directory of hearing care providers (audiologists, hearing instrument specialists, and otolaryngologists). This site is currently under construction. <http://www.betterhearing.org/>

\*Boys Town National Research Hospital has Centers for research and clinical services for hearing loss in children. <http://www.boystownhospital.org/>

\*Central Institute for the Deaf is a unique network of resources central to knowledge and the progressive treatment of adult and childhood deafness. <http://www.cid.wustl.edu/>

\*Clinician's Handbook of Preventive Services courtesy of \*The Virtual Hospital provides information on effective hearing screening of infants and young children. <http://text.nlm.nih.gov/frs/pick?collect=ppip&dbName=ppipc&cd=1&t=918146662>

\*Cochlear Implant Association, Inc. formerly Cochlear Implant Club International, Inc., is a non-profit organization that provides support, information and access to local support groups for adults and children who are cochlear implant recipients or who are interested in learning about cochlear implants. CIA also advocates for the rights of and services for people with hearing loss. <http://www.cici.org/>

\*Collaborative Early Intervention National Training e-Resource (CENTe-R) informs and supports graduate-level professionals serving families with infants and toddlers who are deaf/hard of hearing through web-based training that embraces trans-disciplinary approaches and connections among ongoing learners. <http://sign-language.cente-r.org/>

\*The Combined Health Information Database (CHID) is a database produced by health-related agencies of the federal government. This database provides titles, abstracts, and availability information for health information and health education resources. CHID lists health promotion and education materials and program descriptions that are not indexed elsewhere. <http://chid.nih.gov/>

\*Convention of American Instructors of the Deaf is an organization of educators of the deaf in the United States and Canada with the object of promoting “the education of the deaf on the broadest, most advanced, and practical lines,” and for that purpose “to secure the harmonious union in the organization of all persons actually engaged in educating the deaf in America.” <http://www.caid.org/>

\*Council on Education of the Deaf facilitates informational sharing and collaborative activities within the field of deaf education. <http://www.deafed.net/>

\*DeafKids.com This site has been designed for young Deaf and hard-of-hearing people, age 17 and under. The purpose is to give Deaf/HH kids a place to meet friends, network, share their ideas and keep informed. <http://www.deafkids.com/>

\*Gallaudet University This site provides information on the world's only university for deaf and hard-of-hearing undergraduate students. Graduate degree programs and continuing education courses are available to deaf, hard-of-hearing, and hearing students. <http://www.gallaudet.edu/>

\*Genetics of Congenital Hearing Impairment This site provides information and abstracts from the June 7, 1999 conference hosted by the Centers for Disease Control & Prevention and Gallaudet University. <http://www.cdc.gov/ncbddd/dd/ddgab.htm>

\*Go Hear is dedicated to being the best source of information for families of infants and children diagnosed with a hearing loss and the professionals who work with these individuals. <http://www.gohear.org/>

\*Guide to Clinical Preventive Services, Second Edition The Report of the U.S. Preventive Services Task Force. This site provides information on screening of infants from the Joint Committee on Infant Hearing 1994 Position Statement. <http://www.odphp.osophs.dhhs.gov/pubs/GUIDECPS/>

\*Hearing Exchange Online An online community for the exchange of ideas and information on hearing loss. No matter what method of communication you have chosen, you'll find interesting and supportive information here. <http://www.hearingexchange.com/>

\*Hearing, Speech and Deafness Center A resource center in the Seattle, Washington area for those affected by hearing loss, speech and language impairment, or deafness. <http://www.hsdc.org/>

\*Hereditary Hearing Loss Homepage This site provides current information on genetic causes of hearing loss. <http://www.uia.ac.be/dnlab/hhh/>

\*House Ear Institute (HEI) is a non-profit organization established in 1946 to study the auditory system from the ear canal through the inner ear and into the cortex of the brain. We have sought to improve hearing aids and auditory implants and develop innovative treatments and intervention methods. <http://www.hei.org/>

\*John Tracy Clinic is a non-profit organization providing, worldwide and without charge, parent-centered services to young children with a hearing loss. Services include audiological testing, parent/infant programs, parent classes, a preschool, and a correspondence course. <http://www.jtc.org/>

\*Kresge Hearing Research Institute began research at the University of Michigan – Ann Arbor in 1963 on multi-disciplinary projects in behavior, morphology, physiology, molecular biology and genetics, bioengineering, pharmacology and biochemistry. KHRI attempts to provide the resources and environment both for basic research and for spanning the gap between fundamental research and clinical application. <http://www.khri.med.umich.edu/index.htm/>

\*League for the Hard of Hearing was founded in 1910 as a private non-profit rehabilitation agency for infants, children and adults who are hard of hearing and deaf. The League's Mission is to improve the quality of life for people with all degrees of hearing loss. <http://www.lhh.org/>

\*Marion Downs National Center for Infant Hearing provides information for the coordination of statewide systems for screening, diagnosis, and intervention for newborns and infants with hearing loss. <http://www.colorado.edu/slhs/mdnc/>

\*National Association of the Deaf Web site provides information on programs and activities including grassroots advocacy and empowerment, captioned media, certification of American Sign Language professionals, certification of sign language interpreters, deafness-related information and publications, legal assistance, policy development and research, public awareness, and youth leadership development. <http://www.nad.org/>

\*National Center for Hearing Assessment and Management This site provides information on newborn hearing screening programs, legislation, equipment, and issues. The site also provides an implementation guide, references, and links to other sites. <http://www.infanthearing.org/>

\*National Center on Deafness was founded in 1964 to meet the educational needs of deaf and hard of hearing students at Cal State Northridge. The goal is to make all University services fully accessible to students thus enabling them to maximize the benefits of their education. Services include interpreting, notetaking, academic advising, and job placement services offered at no additional cost to students. <http://ncod.csun.edu/>

\*National Council on Disability is an independent federal agency making recommendations to the President and Congress on issues affecting Americans with disabilities. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities. <http://www.ncd.gov/>

\*National Early Childhood Technical Assistance Center supports the implementation of the early childhood provisions of the Individuals with Disabilities Education Act (IDEA). NECTAC's mission is to strengthen service systems to ensure that children with disabilities (birth through five) and their families receive and benefit from high quality, culturally appropriate, and family-centered supports and services. <http://www.nectas.unc.edu/>

\*The National Information Center for Children and Youth with Disabilities is a centralized source of accurate, up-to-date, objective information on topics dealing with deafness and hearing loss. <http://www.nichcy.org/>

\*National Institute on Deafness and Other Communication Disorders is the federal government's focal point for biomedical and behavioral research in human communication. The Institute supports and conducts research on the normal and disordered processes of hearing, balance, smell, taste, voice, speech and language. This Web site also has the NIDCD Clearinghouse, which disseminates information about disorders of human communication. <http://www.nidcd.nih.gov/>

\*National Policy Center for Children with Special Health Care Needs (NPCSHCN) is concerned with the promotion of complete, family-centered systems of health care for children with special health care needs and their families. The Center is dedicated to producing information that is relevant to benefit managed care organizations, state agencies, families, and program administrators. <http://www.jhsph.edu/centers/cshcn/>

\*National Technical Institute for the Deaf is one of eight colleges of Rochester Institute of Technology, the world's first and largest technological college for students who are deaf or hard of hearing. <http://ntidweb.rit.edu/>

\*Net Connections for Communication Disorders & Sciences provides many valuable resources for professionals and students in communication disorders and sciences as well as for people with communication disabilities and those who are part of their lives. <http://www.communicationdisorders.com>

\*Option Schools OPTION schools are committed to assuring parents across the United States and Canada the option of a quality oral education for their deaf and hard of hearing children. By sharing ideas and expertise, OPTION schools enhance and maintain the strengths of individual programs and provide models of quality education. <http://www.oraldeafed.org/schools/index.html>

\*Otology Online The Web site for the new Shea Center For Ears Hearing & Balance, Inc. was opened in January 1998 by John J. Shea III, M.D. The center stands alone in the mid-south as a resource dedicated solely to the diagnosis and treatment of diseases of the ear and related structures. <http://www.ears.com/>

\*PEPNet Resource Center was established to provide information and technical assistance to postsecondary institutions serving people who are deaf and hard of hearing. <http://www.prc.csun.edu/>

\*The SKI-HI Institute is devoted to providing information for assisting infants, toddlers, and young children with disabilities and their families through research, development, promising practices, training, technical assistance, and information sharing. The Institute is a unit of the College of Education, Department of Communicative Disorders and Deaf Education at Utah State University and is active nationally. The website describes the programs and resources that are available. <http://coe.ed.usu.edu/skihi/index.html>

\*Tech Connections One-stop resource for information on Assistive Technology (AT) designed to accommodate people with disabilities in the workplace and in everyday life activities. <http://www.techconnections.org/index.html>

\*Texas Department of Health-Audiology Services provides hearing-related information and resources within the state of Texas. <http://www.tdh.state.tx.us/audio/audiology.htm>

\*University of Colorado Department of Speech, Language, and Hearing Sciences provides information related to the programs and activities in this university department. This page does not appear to be functioning at the moment. <http://www.colorado.edu/slhs/index.html/>

\*University of Michigan Cochlear Implant Program Provides information about cochlear implants, what they can and can't do, who is a candidate, and to address commonly asked questions. There is also information on the University of Michigan's most recent research on cochlear implants.

<http://www.med.umich.edu/oto/ci/>

\*Virtual Hospital The Virtual Hospital is a digital health sciences library created in 1992 at the University of Iowa to help meet the information needs of health care providers and patients. The goal of the Virtual Hospital digital library is to make the Internet a useful medical reference and health promotion tool for health care providers and patients. <http://www.vh.org/>

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Centers for Disease Control and Prevention**  
National Center on Birth Defects and Developmental Disabilities  
Division of Human Development and Disability  
Early Hearing Detection and Intervention  
1600 Clifton Road  
Atlanta, GA 30333

404-498-3032 (Phone and TDD)  
404-498-3050 (Fax)