



# EHDI 101

2014 National EHDI Meeting

# Presenters

- ❖ Hallie Morrow, MD, MPH, EHDI Systems
- ❖ Karen Hopkins, M.Ed CAGS, Family Centered Early Intervention
- ❖ Marcus Gaffney, MA, Centers for Disease Control and Prevention (CDC) National Structure of EHDI
- ❖ Tabitha Belhorn, BA, Parent Experience
- ❖ Susan E. Wiley, MD, Medical Aspects of EHDI
- ❖ Beth Benedict, Ph.D., Ways to Get Involved

# **EHDI Systems**

Hallie Morrow, MD, MPH

California Department of Health Care  
Services

# How Far Have We Come

- ❖ 1993 - NIH Consensus Development Conference report recommending universal hearing screening
- ❖ 2013 – 45 states have legislation related to newborn hearing screening



# Why Screen Every Baby?

- ❖ Previous strategies missed 50% of the newborns with hearing loss
- ❖ Hearing loss occurs more frequently than any other congenital condition we screen for



# Why Screen Every Baby?



- ❖ The most important factors in language acquisition are:
  - ❖ Age at identification
  - ❖ Parental involvement

# Why Screen Every Baby?

- ❖ Negative consequences of late identification of hearing loss
  - ❖ Delays in expressive and receptive language
  - ❖ Impacts on social, emotional, and cognitive development
  - ❖ Poor academic performance



# National Goals: 1-3-6

- ❖ Every infant will complete hearing screening by **1** month of age
- ❖ Complete audiological evaluation to identify hearing level by **3** months of age
- ❖ Receive appropriate early intervention services by **6** months of age



# Key Stakeholders

- ❖ Federal
  - ❖ Maternal and Child Health Bureau (MCHB)
  - ❖ Centers for Disease Control and Prevention (CDC)
  - ❖ Office of Special Education Programs (OSEP)



# Key Stakeholders

- ❖ National
  - ❖ American Academy of Pediatrics (AAP)
  - ❖ National Center for Hearing Assessment and Management (NCHAM)
  - ❖ Joint Committee on Infant Hearing (JCIH)



# Key Stakeholders

- ❖ State EHDI programs
- ❖ Parents
- ❖ Deaf and hard of hearing adults
- ❖ Deaf and hard of hearing advocates



# Key Stakeholders



- ❖ Parent-to-parent support programs
- ❖ State early intervention programs
- ❖ Local early intervention programs

# Key Stakeholders

- ❖ Hospitals
- ❖ Outpatient Screening Providers
- ❖ Diagnostic Audiology Providers
- ❖ Primary Care Providers
- ❖ AAP Chapter Champions

# Challenges

- ❖ 38% Loss to Follow-up nationally
- ❖ Insurance coverage for hearing screening
- ❖ Reasonable charges for hearing screening
- ❖ Insurance coverage for hearing aids

# Challenges

- ❖ Delays in authorization for diagnostic evaluations
- ❖ Lack of qualified pediatric audiology providers
- ❖ Incomplete diagnostic evaluations
- ❖ Cultural competence

# Challenges

- ❖ Obtaining early intervention information
- ❖ No sense of urgency among PCPs or audiology providers for this developmental emergency





# Successes

- ❖ 98% of infants born in the US were screened in 2011
  - ❖ 95% screened by 1 month of age
- ❖ Over 5,000 infants born in 2011 were identified as deaf or hard of hearing
  - ❖ 71% completed the diagnostic evaluation by 3 months of age
- ❖ 63% of those deaf or hard of hearing infants were known to be enrolled in early intervention
  - ❖ 68% in EI enrolled by 6 months of age

# Successes

- ❖ Some states have developed model programs
- ❖ Quality improvement learning collaboratives



# Successes

- ❖ Innovative technologies – telehealth
- ❖ Parent to parent support programs
- ❖ New collaborative partners



# Questions



# **EHDI**

## **The Federal Role**

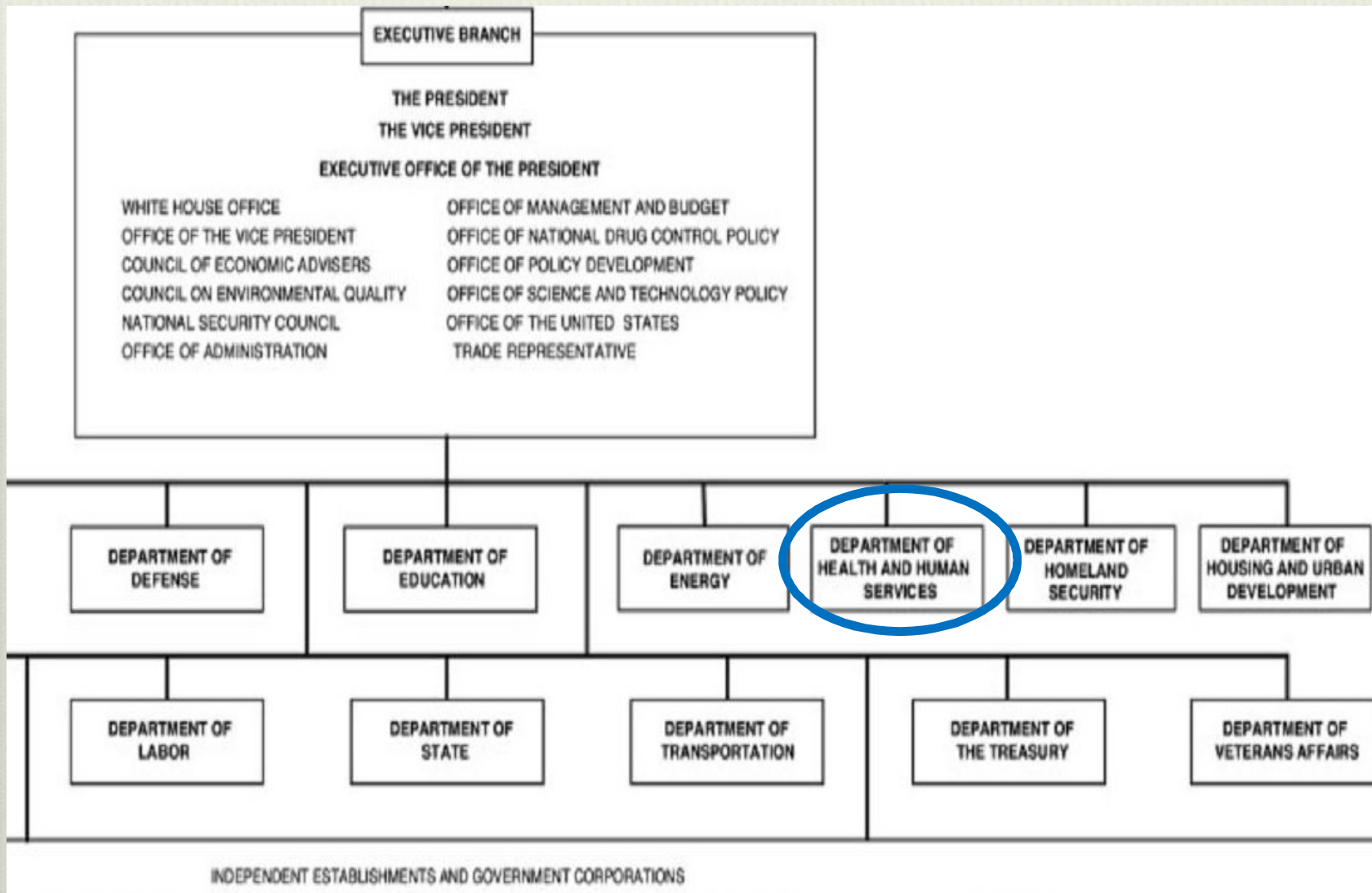
Marcus Gaffney, Acting EHDI Team Lead

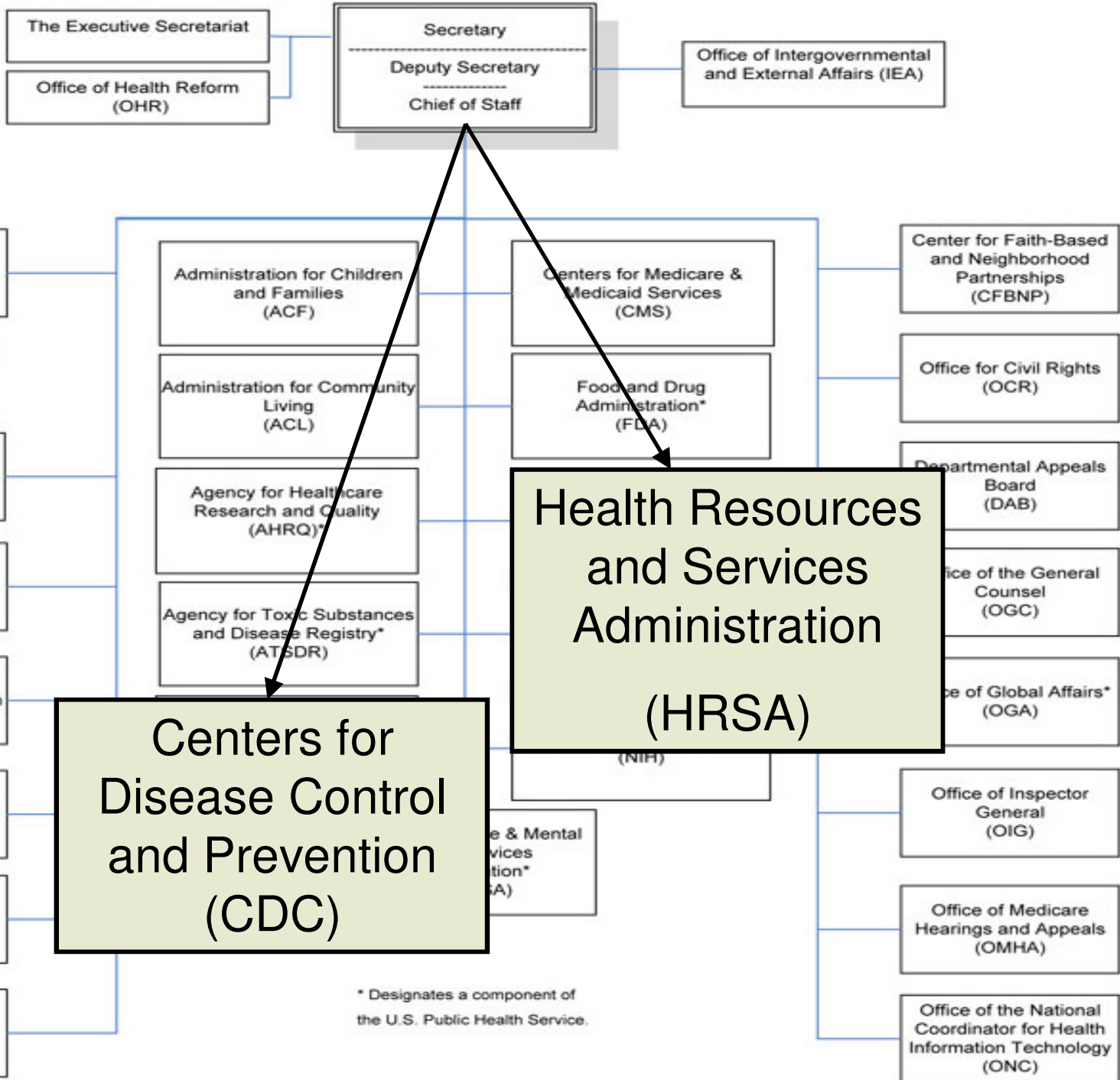
**Centers for Disease Control and Prevention (CDC)**

National Center on Birth Defects and Developmental Disabilities

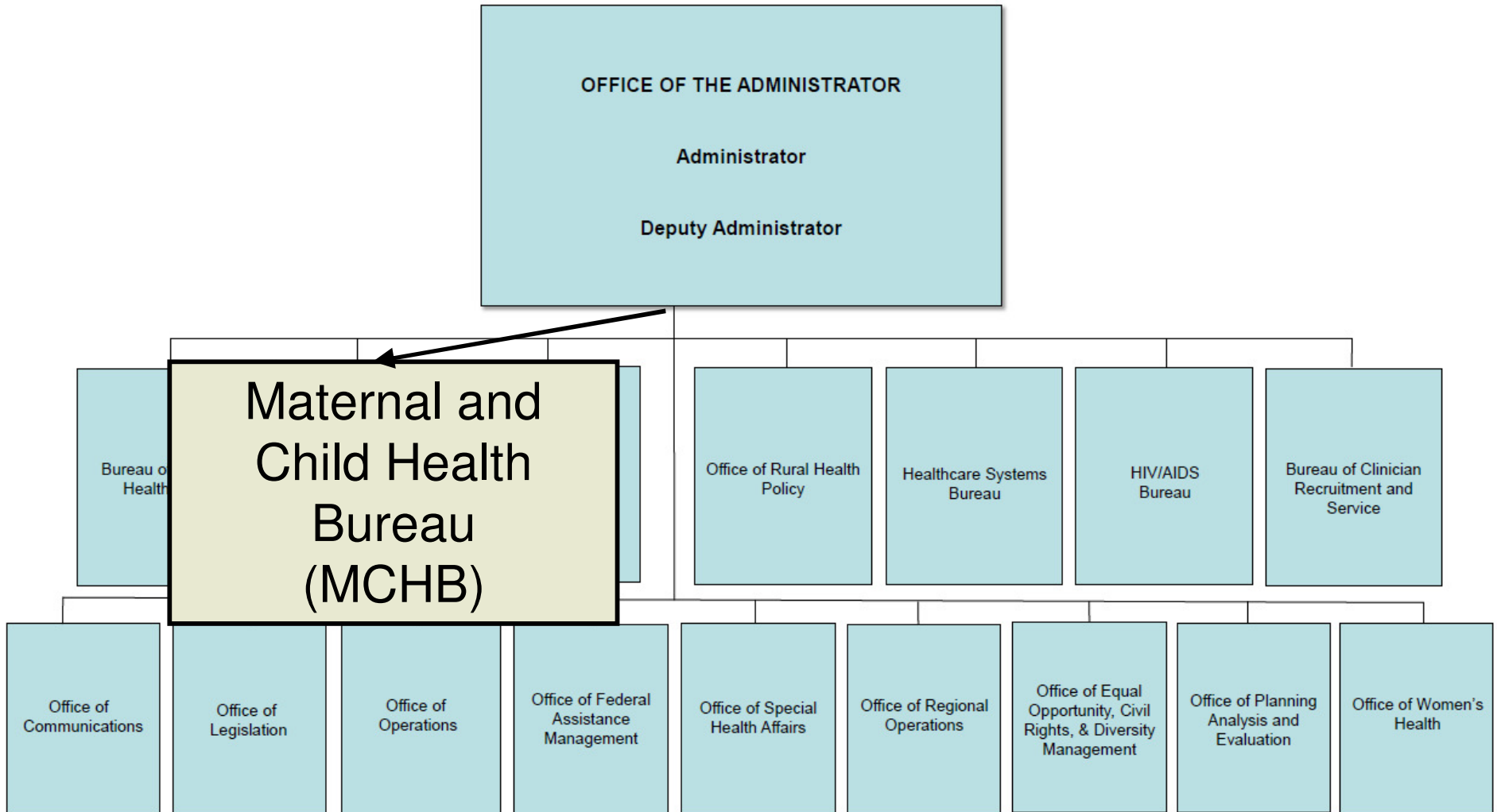
Division of Human Development and Disability

Early Hearing Detection and Intervention Team



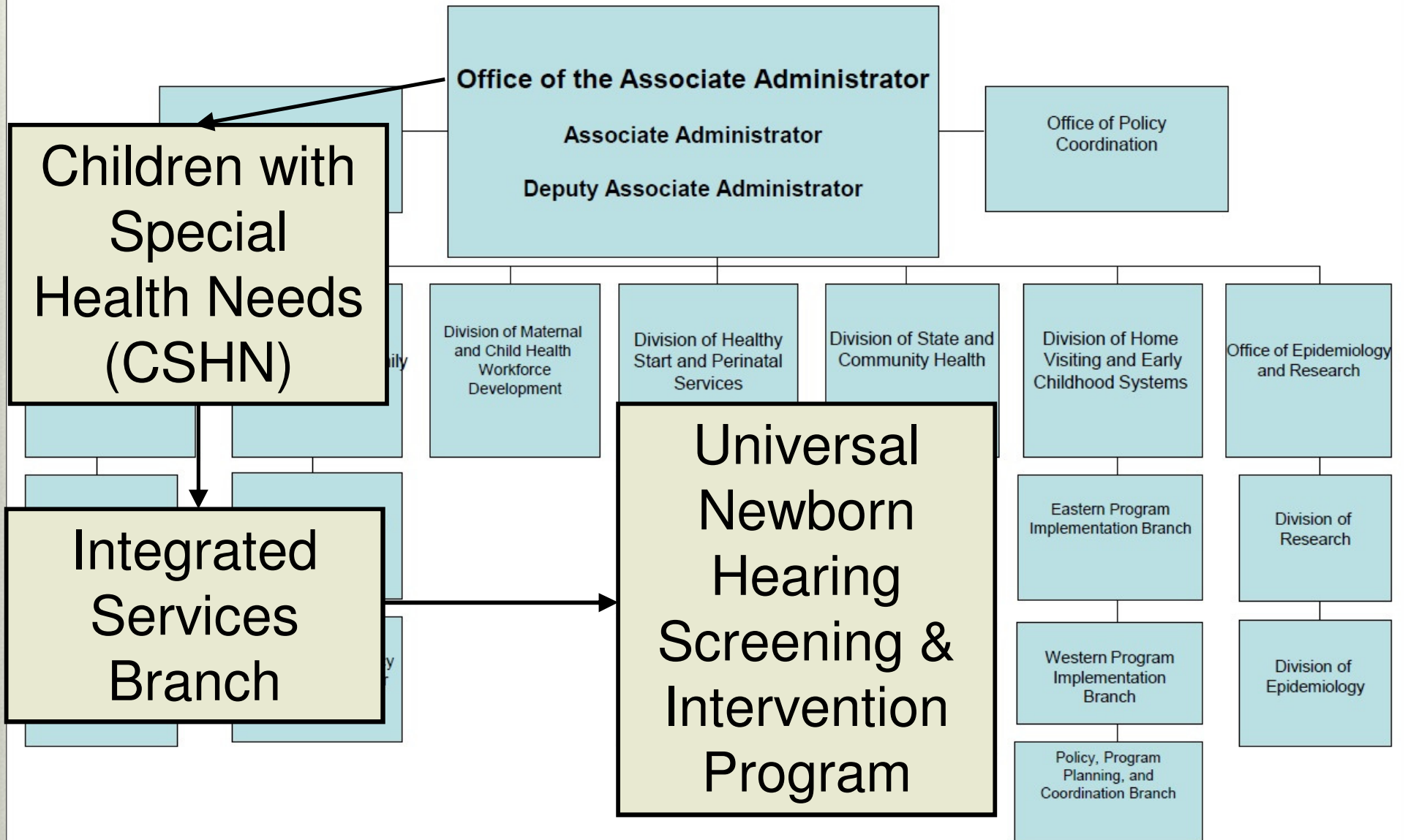


## Health Resources and Services Administration

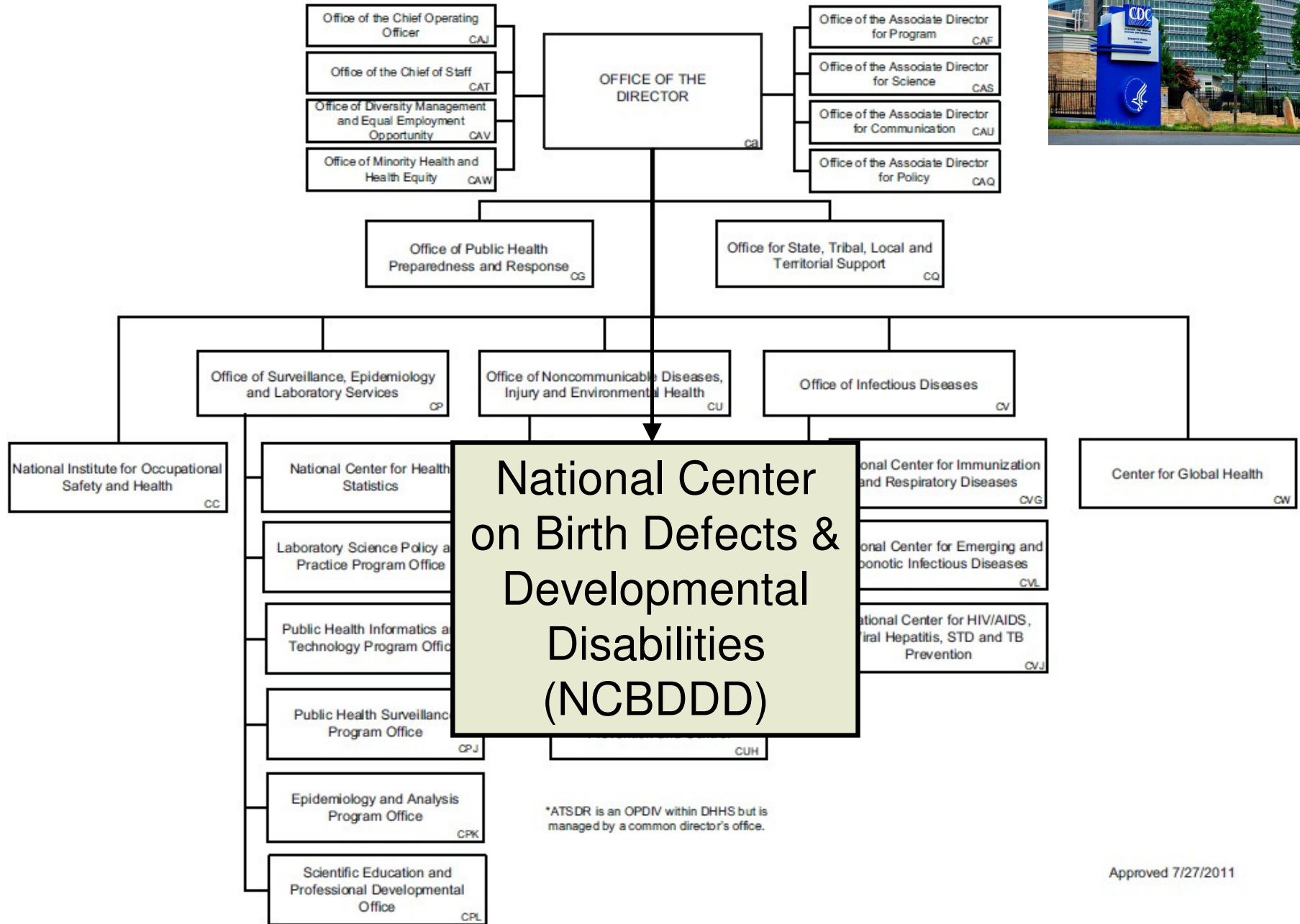




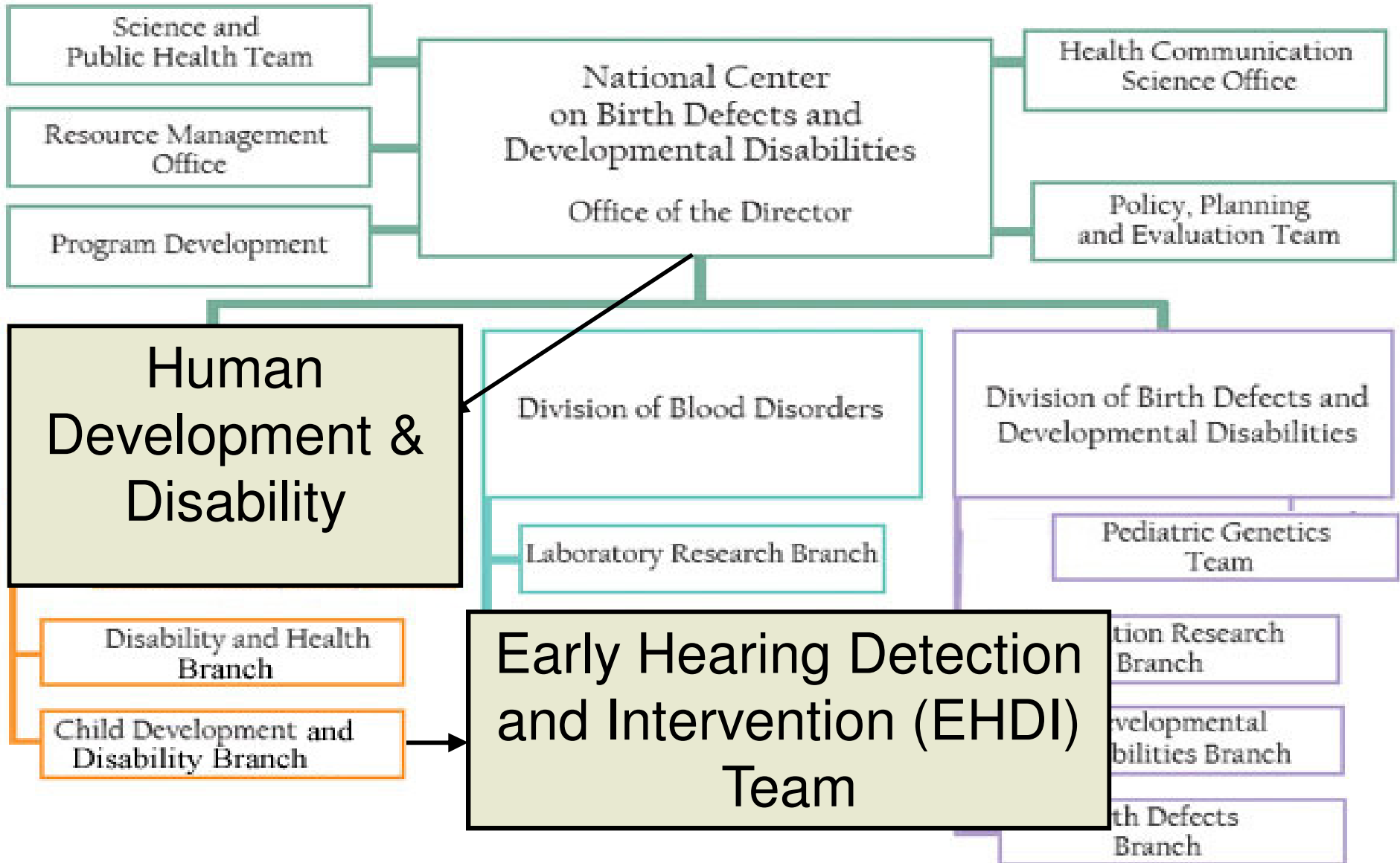
# Maternal and Child Health Bureau



**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**



# NCBDDD Organizational Chart



# 2010 Early Hearing Detection and Intervention Act

HRSA and CDC shall coordinate and collaborate in assisting States to:

- ❖ Establish newborn and infant hearing screening, evaluation, diagnosis and intervention programs and systems
- ❖ Develop a data collection system



Congressional Authority:  
Health Resources and Service Administration  
(HRSA)

**2010 Early Hearing Detection and Intervention Act:**

“Develop statewide newborn and infant screening, evaluation, diagnosis, and intervention programs and systems, and to assist in the recruitment, retention, education, and training of qualified personnel and health care providers”

# Congressional Authority: Activities HRSA

- ❖ Develop and monitor the efficacy of EHDI programs and systems for screening, evaluation and interventions
- ❖ Establish and foster family-to-family support mechanisms
- ❖ Collect data for applied research, program evaluation and policy development
- ❖ Ensure follow-up by a qualified health care provider
- ❖ Adopt models that effectively increase follow-up

# HRSA Funding: Grants

## Maternal and Child Health Bureau (MCHB)

Purpose:

- ❖ Activities to significantly reduce the loss to follow-up of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery
- ❖ Applicants are expected to employ s National Initiative on Child Health Quality (NICHQ) strategies in their programs in order to compete successfully for this grant program

# HRSA MCHB Funding: Cooperative Agreement

National Technical Resource Center for Newborn Hearing Screening and Intervention (*NCHAM* / [www.infanthearing.org](http://www.infanthearing.org))

- ❖ Develop and coordinate educational activities and information
- ❖ Provide a forum for communication between key stakeholders
  - ❖ Convene an annual meeting of CDC and HRSA grantees
- ❖ Maintain a newborn hearing screening expert network



# HRSA MCHB Funding: Cooperative Agreement

National Technical Resource Center for Newborn Hearing Screening and Intervention (NCHAM)

- ❖ Support training opportunities for families and public health practitioners
- ❖ Coordinate with the other MCHB funded National Centers
- ❖ Coordinate with other infant and toddler screening programs
- ❖ Expand screening in new Early Head Start and Head Start sites

# Congressional Authority: Centers for Disease Control and Prevention (CDC)

## 2010 Early Hearing Detection and Intervention Act:

“To provide technical assistance to State agencies to complement an intramural program and to conduct applied research related to newborn and infant hearing screening, evaluation and intervention programs and systems. The program shall develop standardized procedures for data management and program effectiveness and costs”

More about CDC EHDI:

[www.cdc.gov/ncbddd/hearingloss](http://www.cdc.gov/ncbddd/hearingloss)

# Congressional Authority: Activities CDC

- ❖ Ensure quality monitoring of newborn and infant hearing loss screening, evaluation, diagnosis, and intervention programs and systems
- ❖ Provide technical assistance on data collection and management
- ❖ Study the effectiveness of newborn and infant hearing screening, audiologic and medical evaluations and intervention programs and systems
- ❖ Promote the sharing of data regarding early hearing loss

# CDC EHDI Funding: Cooperative Agreements

- ❖ CDC currently funds 52 states and territories

Purpose:

- 1) Assist EHDI programs in developing and maintaining a sustainable, centralized newborn hearing screening EHDI Information Systems (EHDI-IS)
  - Capable of accurately identifying, matching, collecting, and reporting data on all occurrent births that is unduplicated and individually identifiable through the three components of the EHDI process (*screening, diagnosis, and early intervention*)
  - EHDI-IS help programs ensure all infants are screened and receive recommended follow-up services

## CDC EHDI Funding: Cooperative Agreements *(continued)*

- 2) For those programs with fully developed EHDI Information Systems (EHDI-IS), enhance electronic system capacity to collect data, ensure children receive recommended screening and follow-up services, and exchange data accurately, effectively, securely, and consistently
  - Exchange between the EHDI-IS and Electronic Health Record Systems (EHR-S) with a specific focus on reducing the duplicate data entry burden and a reduction in loss to recommended follow-up services

# CDC Recipient Activities

- ❖ Develop and maintain the EHDI-IS to accurately identify, match, and collect data that is unduplicated, and individually identifiable (not estimated or aggregated) through the three components of the EHDI process (screening, diagnosis, and early intervention)
- ❖ Collect and report individualized demographic\* and age specific data for every occurrent birth about the child's status and progress through the three components of the EHDI process

\*As defined in the HSFS (*baby's sex, and maternal age, education, race and ethnicity*)

## CDC Recipient Activities *(continued)*

- ❖ Develop and implement a process for potential reporting sources to monitor the quality and completeness of individualized demographic and age specific EHDI data
- ❖ Collaborate with potential reporting sources to develop data collection and sharing agreements on individual unduplicated EHDI data
- ❖ Develop and implement plans for monitoring progress and evaluating success and accomplishment of the funded activities in terms of completeness, effectiveness, and data quality

## CDC Recipient Activities *(continued)*

- ❖ Analyze and disseminate EHDI data and related analyses to shape the ongoing development of EHDI-IS and inform partners and stakeholders of the program's successes and challenges
- ❖ Contribute data annually to the National CDC EHDI Hearing Screening and Follow-up Survey
  - ❖ [www.cdc.gov/ncbddd/hearingloss/ehdi-data.html](http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)
- ❖ Attendance by two EHDI program staff at the annual National EHDI meeting



# CDA and HRSA Collaborations

- ❖ Provide technical assistance to the states and territories through co-sponsorship of the annual EHDI meeting convened since 2002
- ❖ Participation and coordination in national meetings and organizations including:
  - ❖ Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SAHDNC)
  - ❖ Joint Committee on Infant Hearing (JCIH)
  - ❖ American Academy of Pediatrics (AAP) Task Force on Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention

**The findings and conclusions in this presentation are those of the author(s) and do not necessarily represent the views of the Centers for Disease Control and Prevention**

# Medical aspects of EHDI

Susan Wiley

# Overview of Topics

- ❖ Medical Issues
- ❖ Genetic Testing
- ❖ Medical home
- ❖ AAP activities

# Medical Aspects

## General concepts

- ❖ In general, physicians are very under-educated on care needs related to children who are deaf/hoh
- ❖ Rarely do we get information in training about hearing loss and what we do get is usually very medical (rarely cultural perspective is presented, and often in relationship with the “ethics of cochlear implantation”)
- ❖ The AAP has tried partner with providers outside the medical setting on a broad range of topics related to EHDI to guide physician education to expand beyond the medical aspects and to include the cultural, communication, and intervention needs of children who are deaf/hoh (Pedialink, EQUIPP course)

# Medical Aspects

- ❖ Genetics Testing (also an area which physicians may have variable understanding)
  - ❖ Goals to pursue genetic testing can be varied
  - ❖ Understand other medical concerns associated with a specific condition (examples: Usher Syndrome with progressive vision loss or a syndrome associated with a heart arrhythmia which could cause sudden death)
  - ❖ To help families understand the likelihood of having other children who are deaf/hoh

# “Medical Home”

- ❖ The medical home is a **concept** about **or approach** to care that we should strive to give in primary care settings (pediatricians, family physicians, internal medicine, nurse practitioners)
- ❖ This word home is not intended to replace the broader concept of home, but trying to encourage the medical system to consider a broader approach to providing care
- ❖ The goal is to provide guidance that allows a medical office/system to address and integrate high quality health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner

# Qualities of a Comprehensive Care Provider

- ❖ Accessible
- ❖ Family Centered
- ❖ Continuous
- ❖ Comprehensive
- ❖ Coordinated
- ❖ Compassionate
- ❖ **Culturally Effective**

# American Association of Pediatrics activities

- ❖ “Chapter Champions” for EHDI in each state
- ❖ Taskforce to provide guidance regarding AAP’s role in national agenda towards EHDI and act as liaison and guide for Chapter Champions
- ❖ Work also related to issues around Lost to Follow-up and Physician Education



# Family Centered Early Intervention



# What is Early Intervention?

- ❖ Early Intervention is a coordinated and comprehensive system of programs, services, and resources that are designed to meet the physical, intellectual, language, speech, social and emotional needs of children from birth to three years who have been identified as having a developmental delay or who are at risk for developing a delay. (Beginnings)

# Principles of Effective Early Intervention

- ◆ Family Centered
- ◆ Culturally Responsive
- ◆ Collaboration With Families and Professionals
- ◆ Hearing, Deaf and Hard of Hearing Partnerships
- ◆ Developmentally Appropriate

# Maine's Early Childhood and Family Services



Maine's Family Centered Early  
Intervention.....changes focus... slows  
the process down a bit.....

Infant identification vs. family focus

Immediate info vs. introducing ideas

Action vs. attachment and bonding

Relationship building.....

# Early Intervention...Strength Based...Culturally Responsive and Community Based



- ❖ Tell me about your baby.
- ❖ Tell me about your family.
- ❖ Who gives you support?
  - ❖ Friends, neighbors, church
- ❖ What are your interests, jobs, or hobbies?
- ❖ In what ways do you like to receive information?

# Collaboration Between Families and Professionals.....

Subtle process.....

- ❖ Becoming a team
- ❖ Realizing roles
- ❖ Identifying outcomes
- ❖ Implementing a plan (IFSP)
- ❖ Evaluating progress
- ❖ Changing as desired



Blasco, EI Services.2001

# Communication and Language Opportunities

- ❖ The concept of “informed choice” reflects the fundamental belief that families need comprehensive, meaningful, relevant and evidence-based information from professionals in order to make decisions that are most appropriate for their child.” (Young et al., 2006)
- ❖ Role of Deaf and Hard of Hearing Children and Adults is critical – Deaf and Hard of Hearing Partnerships





# Assessment-Based Programming

- ❖ Early Learning Standards
- ❖ Monitoring Procedures embedded into the IFSP
- ❖ Communication Plans
- ❖ Assessment should involve the family and be developmentally appropriate
- ❖ Outcomes should be based on assessments and family's priorities

# Early Intervention should be Developmentally Appropriate

“a framework, a philosophy, or an approach to  
working with young children  
(Bredekamp&Rosegrant, 1992, p.4)

Focus:

child development

the individual child and family

social and cultural contexts

(Copple&Bredekamp, 2009)



# Qualified Providers are Critical.....

- ❖ Specialized training in early intervention for children who are deaf or hard of hearing
- ❖ Training in adult learning –working with families (coaching model)
- ❖ EI Providers must be knowledgeable about two different models of the deaf experience:
  - ❖ Deafness as a medical condition
  - ❖ Deafness as a life experience and/or cultural community(Beyond Newborn Hearing Screening Marge and Marge 2005)
- ❖ Deaf and Hard of Hearing Partnerships

## A Final Thought From a Parent.....

“What we really want, really need as parents, is opportunities to contact other families with deaf children, help in making regular contact with adults who are Deaf and Hard of Hearing, information that is accurate, honest, unbiased, and fair, and then the emotional support from our early interventionist to make the decisions that are right for us and our child.”

# Our Family's Journey

Tabitha Belhorn, B.A.

Parent of a Deaf child

# Before Early Intervention

- ❖ A New Life
- ❖ Hindsight is 20/20
- ❖ Diagnosis

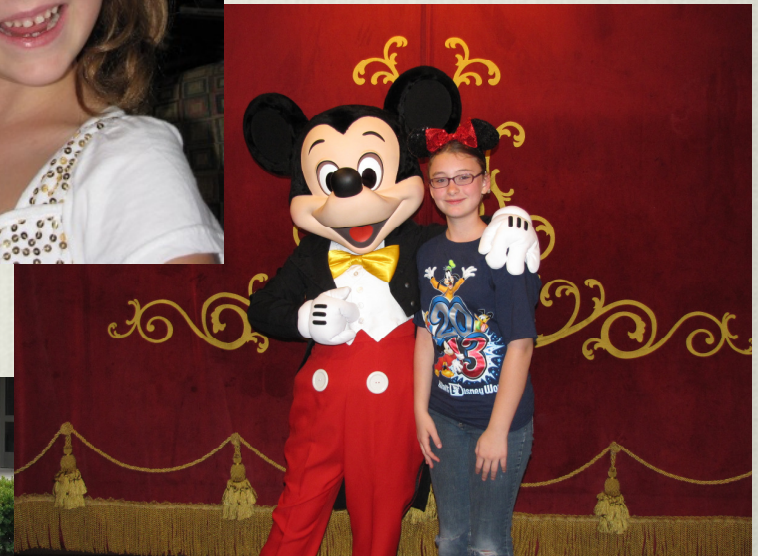
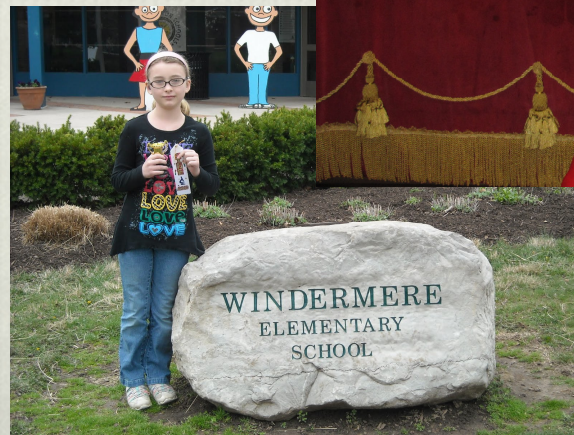


# The Early Intervention Years

- ❖ Referral
- ❖ Our State System
- ❖ Services
- ❖ Achievements
- ❖ Challenges

# After Early Intervention

- ❖ Successes
- ❖ Challenges
- ❖ Why Parents Need EI





# Ways to Get Involved

- ❖ History of EHDI conference
  - ❖ Interpreting services
  - ❖ Deaf Presenters
  - ❖ Workshops focusing on American Sign Language
  - ❖ Planning Committee
    - ❖ Review Subcommittees
  - ❖ Exhibition Booths
  - ❖ Deaf town
  - ❖ Plenary Presenters
    - ❖ History Through Deaf's Eyes
    - ❖ National Association of the Deaf Executive Director, Howard Rosenblum
    - ❖ College Students Reflecting Their Experiences Growing Up Panel
    - ❖ New Insights from the Neural Foundations of Language, The Bilingual Brain, and the Visual Phonological Mind
- ❖ Gallaudet students

# Ways to Get Involved

- ❖ Joint Committee on Infant Hearing (JCIH)
  - ❖ Alexander Graham Bell Association for the Deaf and HH
  - ❖ American Academy of Pediatrics
  - ❖ American Academy of Audiology
  - ❖ American Academy of Otolaryngology- Head and Neck Surgery
  - ❖ American Speech-Language-Hearing Association
  - ❖ Council of Education of the Deaf
  - ❖ Directors of Speech and Hearing Programs in State Health and Welfare Agencies
- ❖ **Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs**
- ❖ **Year 2013: Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention Following Confirmation That a Child Is Deaf or Hard of Hearing**

# Ways to Get Involved

- ❖ National Center for Hearing Assessment and Management (NCHAM)
  - ❖ Centers for Disease Control and Prevention (CDC)
  - ❖ Maternal and Child Health Bureau (MCHB)
  - ❖ Health Resources and Services (HRSA)
  - ❖ [www.infanthearing.org](http://www.infanthearing.org)
  - ❖ EHDI E-Book
  - ❖ Communicating With Your Child Booklet
- ❖ State Advisory Councils
- ❖ State EHDI conferences
- ❖ Deaf Mentor Programs

# EHDI Meeting, 2014

- ❖ Plenary Presenters
- ❖ Concurrent workshops
- ❖ State meetings
- ❖ Poster session
- ❖ Parents sessions (p.9)
- ❖ Students opportunities (p.10)
- ❖ Evening programs
  - ❖ Movie Night: Deaf Children and Their Families in Media
  - ❖ Light reception

# Thanks!

