



EHDI 101

2015 National EHDI Meeting

Presenters

- ❖ Hallie Morrow, MD,
MPH, EHDI Systems
- ❖ Marcus Gaffney, MA,
Centers for Disease
Control and Prevention
(CDC) National
Structure of EHDI
- ❖ Susan E. Wiley,
MD, Medical
Aspects of EHDI
- ❖ Any Hunt, M.S
Early Intervention
- ❖ Tabitha Belhorn, BA,
Parent Experience
- ❖ 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

Challenges

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



Successes

- ❖ 97% of infants born in the US were screened in 2012
 - ❖ 86% screened by 1 month of age
- ❖ Over 5,400 infants born in 2012 were identified as deaf or hard of hearing
 - ❖ 59% identified by 3 months of age
- ❖ 62% of those deaf or hard of hearing infants were known to be enrolled in early intervention
 - ❖ 67% 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
EHDI Team Lead

Centers for Disease Control and Prevention (CDC)
National Center on Birth Defects and Developmental Disabilities
Early Hearing Detection and Intervention (EHDI) Team

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

Why are CDC and HRSA Interested in Deaf and Hard of Hearing Children (D/HH)?

- ❖ Estimate 1-3 of every 1,000 births are D/HH
- ❖ Average age of identification without newborn hearing screen is $\sim 2 \frac{1}{2}$ years
- ❖ “Sensitive period” in all children for both visual and spoken language development
 - ❖ Earlier D/HH children start getting services, the more likely they are to reach their full potential
- ❖ Authorized by Congress

Caution!



- ❖ Organizational Charts
- ❖ Multiple Acronyms
 - ❖ Early Hearing Detection and Intervention (**EHDI**)
 - ❖ Health and Human Services (**HHS**)
 - ❖ Health Resources and Services Administration (**HRSA**)
 - ❖ Centers for Disease Control and Prevention (**CDC**)



The Executive Secretariat
Office of Health Reform (OHR)

Dept. of Health and Human Services (HHS)

Office of Intergovernmental and External Affairs (IEA)

Office of the Assistant Secretary for Administration (ASA)
Program Support Center (PSC)
Office of the Assistant Secretary for Financial Resources (ASFR)
Office of the Assistant Secretary for Health* (OASH)
Office of the Assistant Secretary for Legislative Affairs (ASL)
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Office of the Assistant Secretary for Preparedness and Response* (ASPR)
Office of the Assistant Secretary for Public Affairs (ASPA)

Administration for Children and Families (ACF)
Administration for Community Living (ACL)
Agency for Healthcare Research and Quality (AHRQ)*
Agency for Toxic Substances and Disease Registry* (ATSDR)

Centers for Medicare & Medicaid Services (CMS)
Food and Drug Administration* (FDA)

Health Resources and Services Administration (HRSA)

Centers for Disease Control and Prevention (CDC)

National Institutes of Health* (NIH)

Substance Abuse & Mental Health Services Administration* (SAMHSA)

Center for Faith-Based and Neighborhood Partnerships (CFBNP)
Office for Civil Rights (OCR)
Departmental Appeals Board (DAB)
Office of the General Counsel (OGC)
Office of Global Affairs* (OGA)
Office of Inspector General (OIG)
Office of Medicare Hearings and Appeals (OMHA)
Office of the National Coordinator for Health Information Technology (ONC)

* Designates a component of the U.S. Public Health Service.

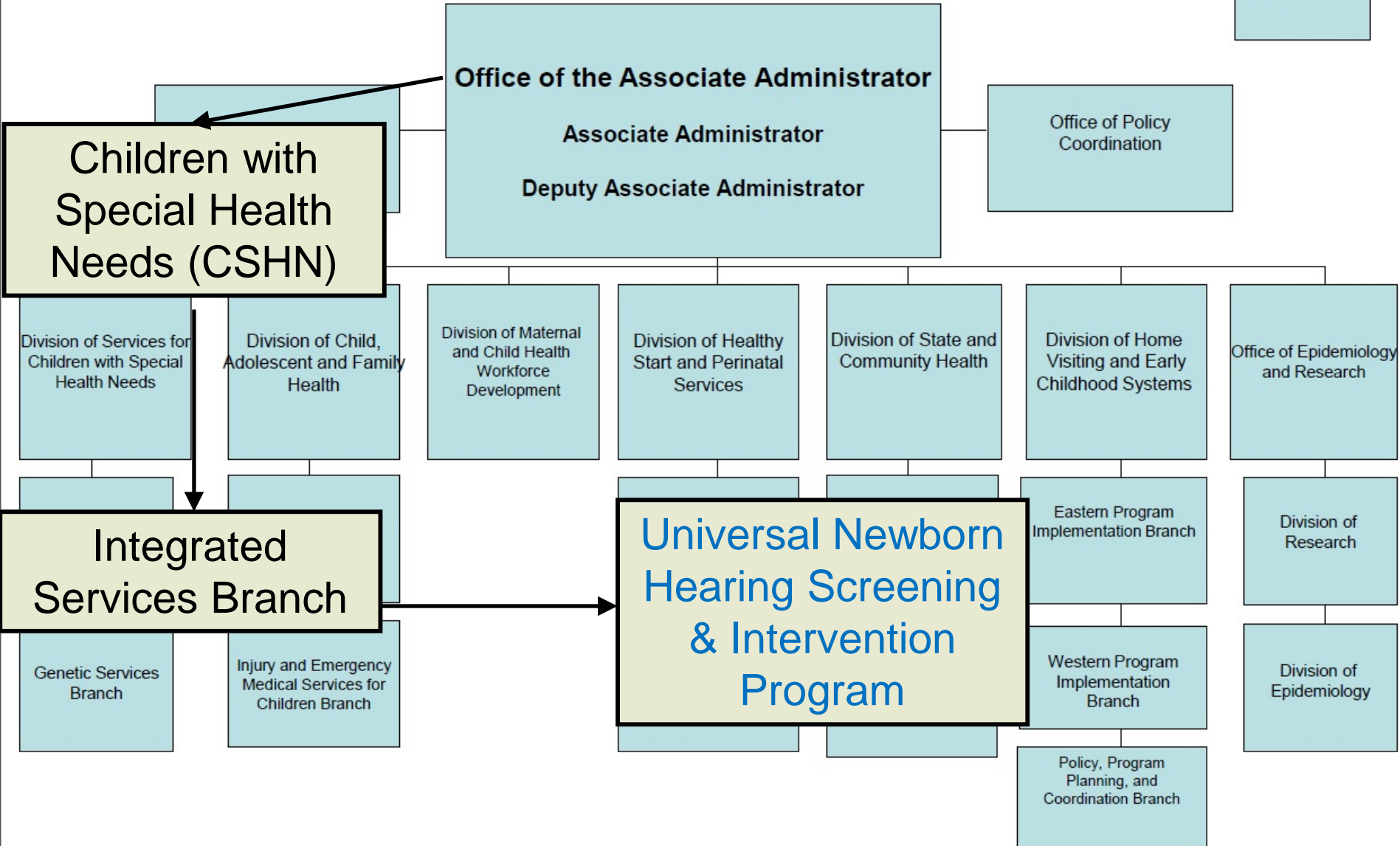
- ❖ **Health Resources and Services Administration (HRSA)**
 - ❖ Primary agency for improving access to health care by strengthening the health care workforce, building healthy communities and achieving health equity.
 - ❖ Programs provide health care to people who are geographically isolated, economically or medically vulnerable.

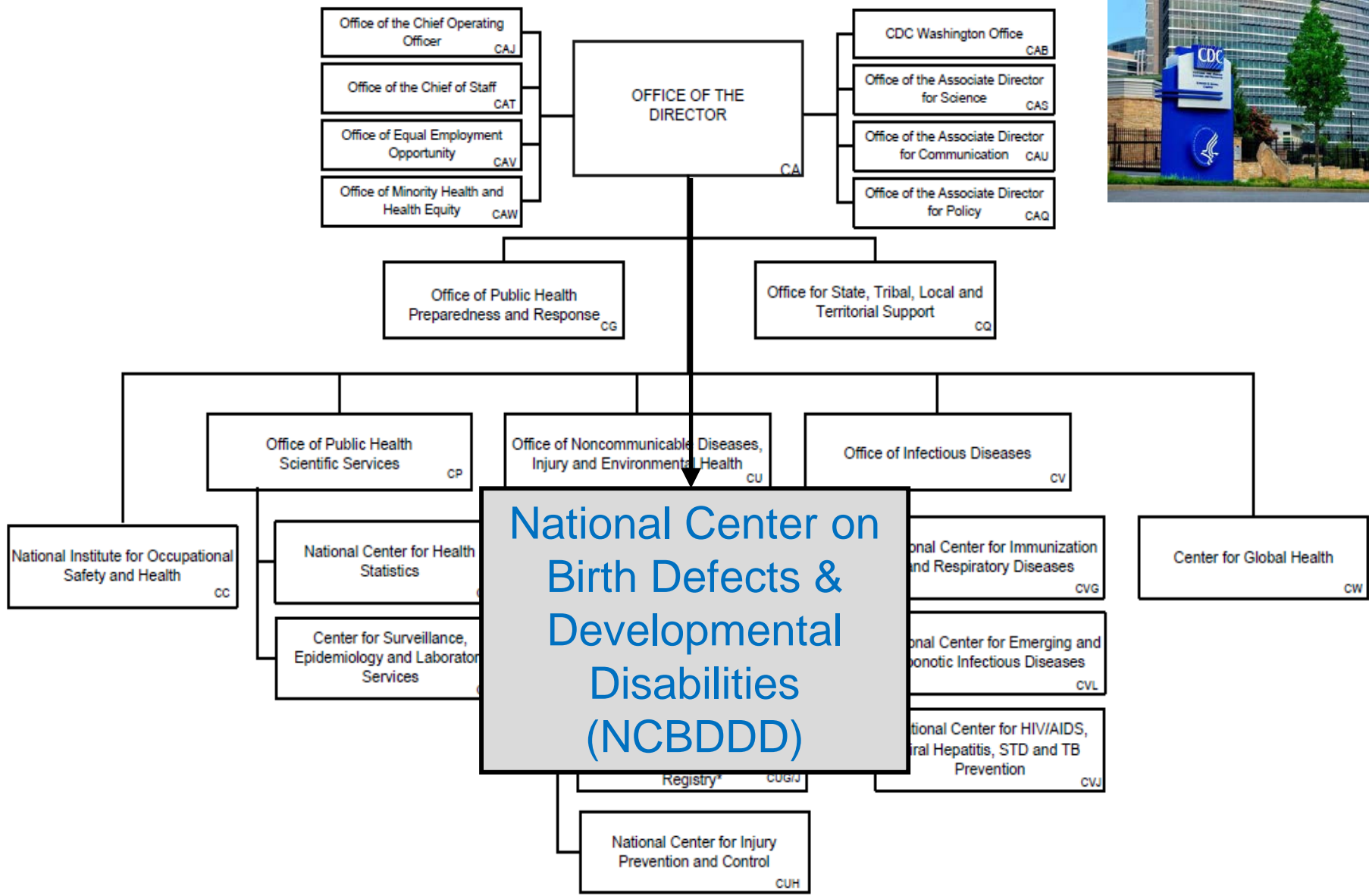
- ❖ **Centers for Disease Control and Prevention (CDC)**
 - ❖ Nation's health protection agency
 - ❖ Conducts critical science and provides health information
 - ❖ Promotes healthy and safe behaviors, communities and environment
 - ❖ Takes the health pulse of our nation

Health Resources and Services Administration (HRSA)

Maternal and Child Health Bureau

02/24/2012





National Center on Birth Defects & Developmental Disabilities (NCBDDD)

*ATSDR is an OPDIV within DHHS but is managed by a common director's office.

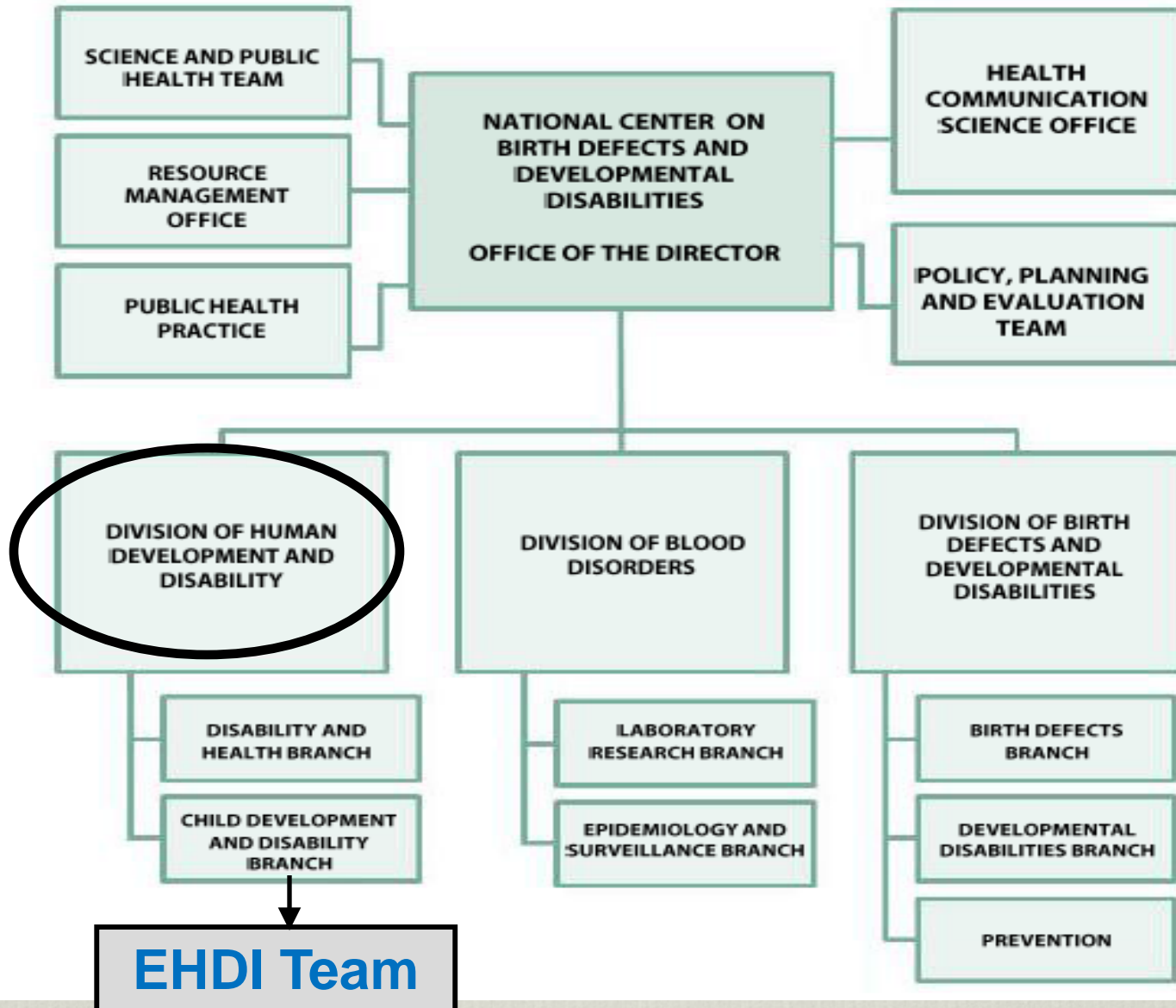
The National Center on Birth Defects and Developmental Disabilities (NCBDDD)

www.cdc.gov/ncbddd

- ❖ The Children's Health Act of 2001, passed by Congress and signed into law by former President Clinton, required the establishment of the NCBDDD at CDC.
- ❖ Mission is to promote the health of babies, children and adults and to enhance the potential for full, productive living.



CDC – NCBDDD



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



CDC and HRSA: Basics

- ❖ Programs started in 2000
 - Assist states and territories

- ❖ Support Joint Committee on Infant Hearing

- ❖ Help children reach their full potential
 - Ensure families know if their child is deaf or hard of hearing
 - Do not recommend or favor any particular early education or communication option
 - Families choose the options that fit their child's unique needs

Congressional Authority: **HRSA**

2010 EHDI 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:

HRSA Activities

- ❖ 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

What is HRSA Doing?

Grants

- ❖ Support activities to reduce the loss to follow-up of infants who have not passed a newborn hearing screening examination prior to discharge from the newborn nursery
- ❖ Grantees use National Initiative on Child Health Quality (NICHQ) strategies in their programs in order to compete successfully for this grant program

HRSA: **Cooperative Agreement**

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

- ❖ Develop and coordinate educational activities and information
- ❖ Provide a forum for communication between key stakeholders
- ❖ Maintain a newborn hearing screening expert network
- ❖ Support training opportunities for families and public health practitioners
- ❖ Coordinate with other infant and toddler screening programs

Congressional Authority: CDC

2010 EHDI 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”

Congressional Authority:

CDC Activities

- ❖ 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
- ❖ Promote the sharing of data regarding early hearing loss

What is CDC Doing?

Cooperative Agreements

- 1) Assist programs in developing and maintaining an EHDI Information Systems (EHDI-IS)
 - Accurately identify, collect, and report data on all births through the EHDI process (*screening, diagnosis, and early intervention*)
 - EHDI-IS help programs ensure all infants are screened and receive recommended follow-up services

- 2) Support enhancing capacity to collect data, ensure children receive recommended services, and exchange data
 - Exchange between the EHDI-IS and Electronic Health Record Systems (*e.g., reduce duplicate data entry and loss to follow-up*)

CDA and HRSA Collaborations

- ❖ Provide technical assistance to states and territories
 - Discuss and coordinate activities
 - Co-sponsor webinars
 - Data sharing

- ❖ Participation and coordination in national meetings and organizations including:
 - Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC))
 - Joint Committee on Infant Hearing (JCIH)

Thank you



Marcus Gaffney

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www.cdc.gov/ncbddd/hearingloss

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
- ◆ Parent to Parent Support

Family Centered Early Intervention

changing the focus...

slowing 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 Oriented



- ❖ 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

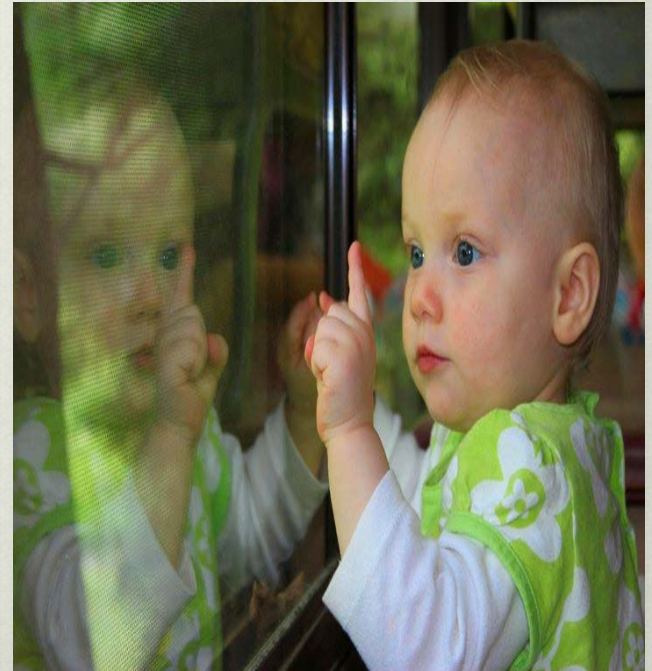
“a framework, a philosophy, or an approach to working with young children”

(Bredekamp&Rosegrant, 1992, p.4)

Focus:

- ❖ Child development
- ❖ 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)
- ❖ 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
- ❖ Parent to Parent Support

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

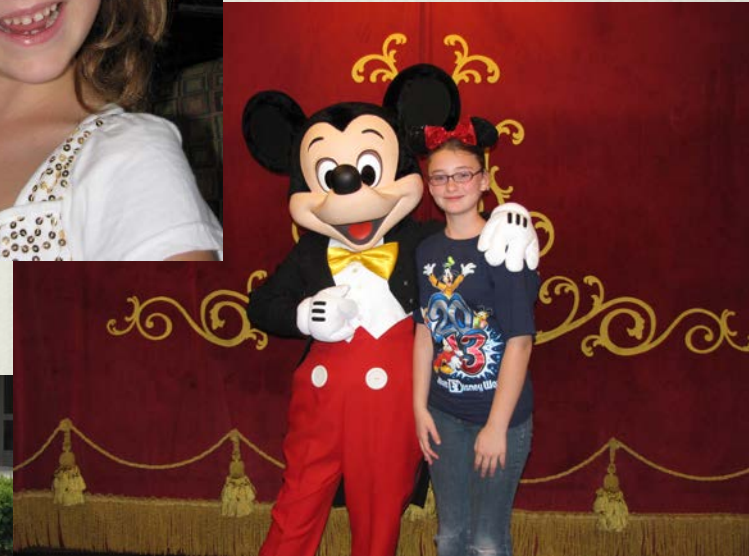
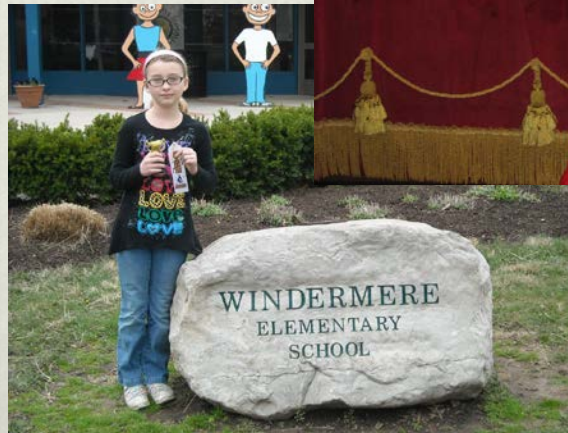


The Early Intervention Years

- ❖ 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
 - ❖ EHDI E-Book
 - ❖ Communicating With Your Child Booklet
- ❖ State Advisory Councils
- ❖ State EHDI conferences
- ❖ Deaf Mentor Programs

EHDI Meeting, 2015

- ❖ Plenary Presenters
- ❖ Concurrent workshops
- ❖ State meetings
- ❖ Poster session
- ❖ Parents sessions (p.9)
- ❖ Students opportunities (p.10)
- ❖ Evening programs
 - ❖ Light reception
 - ❖ Mingle, mingle and mingle

Thanks!

