Data Activity Updates from NCBDDD's Division of Human Development and Disability

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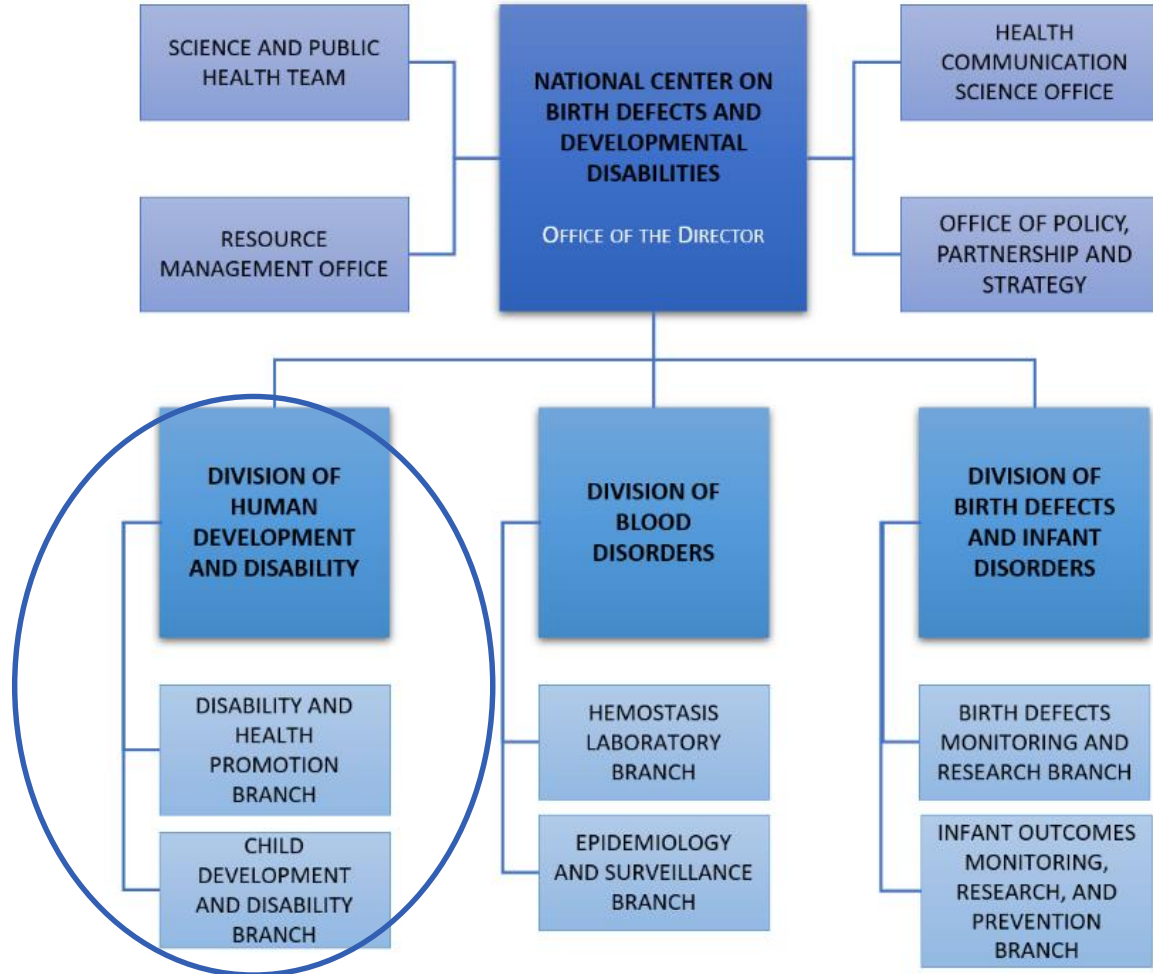
Division of Human Development and Disability

National Center on Birth Defects and Developmental Disabilities

February 11, 2020

Outline

- Organizational structure

- Early Hearing Detection & Intervention (EDHI)

- Autism and Developmental Disabilities Monitoring (ADDM) Network

- Autism Data Visualization Tool

- Disability and Health Data System

- State Medicaid Project

- PRAMS Collaboration

- Population-level Data sources

NCBDDD Organizational Chart

Division of Human Development & Disability

Early Childhood, Readiness, and Wellness

- **Early Hearing Detection & Intervention**
- Children's Emergency Preparedness
- Fragile X Syndrome
- **Autism monitoring and risk factor surveillance**
- Early identification and referral of Developmental Delays and Disabilities
- Child Development Studies
  - Children's Mental Health
  - Attention-Deficit / Hyperactivity Disorder
  - Tourette Syndrome

Young Adult/ Successful Healthcare Transition

- Autism
- ID/DD

- Disability & Health Programs and Activities
  - State Disability and Health Programs
  - National Centers on Disability
  - Partnerships to Promote Best Practices
- **Disability & Health Data in Surveys**
- **Disability & Health Data System**
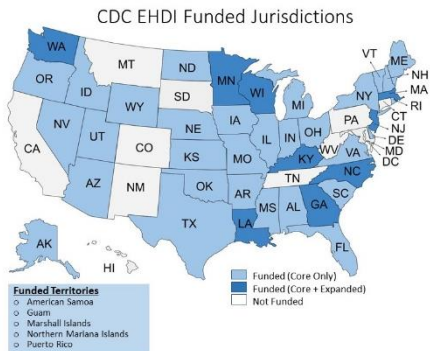- **Utilization of Medicaid data**

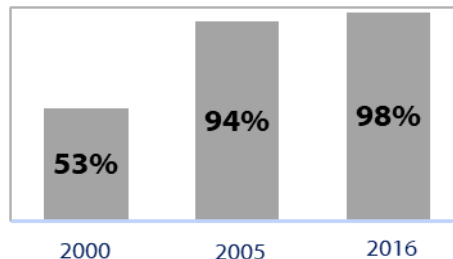**Optimal Health for Adults with Disabilities**

CDC Early Hearing Detection & Intervention (EHDI)

- Support the early identification of children who are deaf or hard of hearing
  - Ensure all infants are screened and receive recommended follow-up services

- Focus Areas
  - Funding and technical assistance to jurisdictions on tracking and surveillance
  - Data collection, analyses, and use

- CDC Hearing Screening and Follow-up Survey
  - Annual survey of jurisdictions about the receipt of services and infants identified
  - Data used to assess progress and identify areas for further improvement
  - Available data for 2005 – 2017 (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)
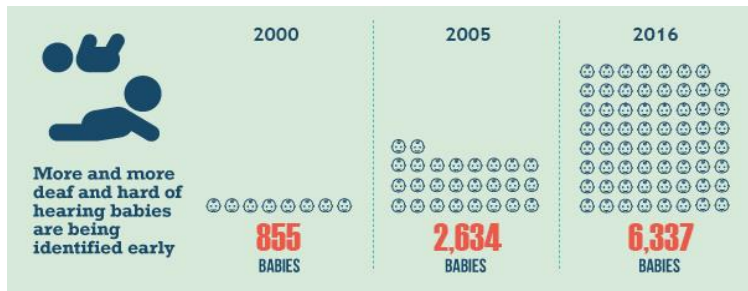
Early Hearing Detection and Intervention (EHDI)

CDC EHDI Funded Jurisdictions

Funded (Core Only)
Funded (Core + Expanded)
Not Funded

Funded Territories
- American Samoa
- Guam
- Marshall Islands
- Northern Mariana Islands
- Puerto Rico

Progress in Hearing Screening

53% — 2000
94% — 2005
98% — 2016

More than **98% of US-born infants** are now screened for hearing loss, **usually before leaving the hospital** [1]

More and more deaf and hard of hearing babies are being identified early

2000	2005	2016
855 BABIES	2,634 BABIES	6,337 BABIES

6,300 Deaf or Hard of Hearing infants were identified early or pre-symptomatically in 2016 – up from 2,700 infants in 2005 [1]

Ensuring all infants receive recommended services and do not become **loss to follow up** or **loss to documentation** is a priority

$200 million in annual special education costs are saved in the U.S. due to newborn hearing screening [2]

CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network

The ADDM Network monitors prevalence of ASD and other indicators

- Age at first comprehensive developmental evaluation

- Age at first autism diagnosis

- % with I.D.

Implemented in

- 11 sites: 4- and 8-year-old surveillance

- 5 sites: 16-year-old follow-up

Next reports will be April 2020 that provide ASD prevalence data for 8- and 4-year-olds using previous method (SY2016)

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Years 2018 and 2020

★ Tracking Autism among 4- and 8-year-olds

★ Tracking Autism among 4- and 8-year-olds AND Follow-up of 16-year-olds

In selected communities

CDC's Autism Data Visualization Tool

- Interactive website provides up-to-date prevalence data on autism relevant to your community across four different data sources
  - CDC's Autism and Developmental Disabilities Monitoring Network
  - Medicaid Analytic eXtract (MAX)
  - Special Education Child Count
  - HRSA's National Survey of Children's Health
- Describes how each data source produces autism prevalence estimates

Criteria   Sample Size   Method

www.cdc.gov/ncbddd/autism/data
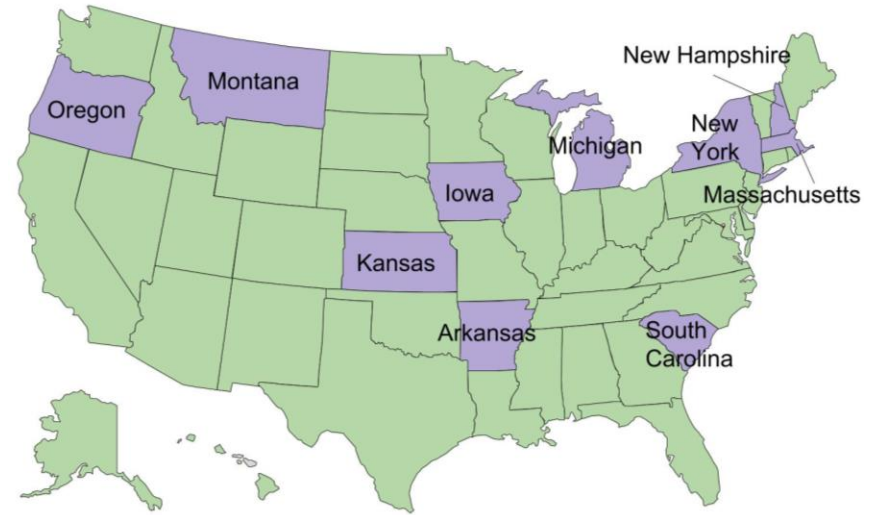
Disability and Health Data System (DHDS)

- 2016 - 2017 data analyzed from Behavioral Risk Factor Surveillance System

  - Disability status & types (hearing, vision, cognition, mobility, self-care, & independent living)

  - 30 health topics, including smoking, obesity, heart disease, & diabetes

- Interactive maps, state profiles, and dual area profiles

- DHDS instructional videos

Disability Data at your Fingertips

Use DHDS to help improve the health and well-being of adults with disabilities.

Visit DHDS at https://dhds.cdc.gov.

DISABILITY & HEALTH DHDS DATA SYSTEM

Find at: https://dhds.cdc.gov

Medicaid Data

- Fund 10 states to access and utilize Medicaid data within their state to identify patterns of health and health care utilization for people with IDD

Recent Publications

- [Using Medicaid data to characterize persons with IDD in five US states](#) [3]

- [Disparities in diabetes management among Medicaid recipients with intellectual and developmental disabilities (IDD): Evidence from five U.S. states](#) [4]

Pregnancy Risk Assessment Monitoring System (PRAMS) Collaboration

- Collaboration between NICHD/NCMRR, CDC/DRH, CDC/NCBDDD

- PRAMS

  – Ongoing, population-based surveillance system

  – Self-reported maternal behaviors and experiences collected 2-6 months after delivery

  – Disability supplement

    • WG-Short Set; 6 questions

    • Data collection began January 2019 in 24 states

- Purpose is to understand pregnancy experiences and outcomes among women with disabilities

www.cdc.gov/prams

Population-based Data

- Health surveys
  - Behavioral Risk Factor Surveillance System (BRFSS)
  - National Health Interview Survey (NHIS)
  - National Health and Nutrition Examination Survey (NHANES)

- Other surveys
  - American Community Survey (ACS)
  - Survey of Income and Program Participation (SIPP)
  - National Survey on Drug Use and Health (NSDUH)

Disability and Health

Disability & Health Home

- Disability & Health Home
- Disability & Health Overview
- Disability Inclusion +
- Disability & Health Healthy Living +
- Disability & Health Emergency Preparedness +

Data & Statistics −

- Disability & Health Data System (DHDS)
- Disability Datasets
- Healthcare Cost Data
- Disability & Health U.S. State Profile Data: Adults 18+ years of age +

Articles & Key Findings +

www.cdc.gov/ncbddd/disabilityandhealth/datasets.html

Resources

- CDC's Hearing Loss in Children www.cdc.gov/ncbddd/hearingloss/
  - CDC Hearing Screening and Follow-up Survey www.cdc.gov/ncbddd/hearingloss/ehdi-data.html
- CDC's Autism Spectrum Disorder www.cdc.gov/ncbddd/autism/
  - Autism Data Visualization Tool www.cdc.gov/ncbddd/autism/data
- CDC's Disability and Health www.cdc.gov/ncbddd/disabilityandhealth/
  - Disability and Health Data System https://dhds.cdc.gov
  - Disability Datasets www.cdc.gov/ncbddd/disabilityandhealth/datasets
- CDC's Pregnancy Risk Assessment Monitoring System www.cdc.gov/prams

References

1. Centers for Disease Control and Prevention [CDC]. Annual Data Early Hearing Detection and Intervention (EHDI) Program. https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html.

2. Grosse S. Education cost savings from early detection of hearing loss: new findings. Volta Voices 2007;14:38–40

3. McDermott S et al. Using Medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. Am J IDD 2018; 123(4): 371-81

4. Lu Z et al. Disparities in diabetes management among medicaid recipients with intellectual and developmental disabilities (IDD): Evidence from five U.S. states. Disabil Health J 2019; [Epub ahead of print]

Thank you!

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348   www.cdc.gov