

CDC Update: Data Related Activities

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CDC EHDI

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2022 EHDI Coordinators Meeting Updates



- Collecting Family-to-family support information
 - CDC Hearing Screening and Follow-up Survey (HSFS)
- Outcomes and Developmental Data Assistance Center for EHDI (ODDACE) Programs
- EHDI Outcome Committee

Collecting Family-to-Family Support Data: HSFS



- Area of interest to partners and CDC.
 - Support the (FEHDI) Data Project (www.infanthearing.org)
 - Awareness not all programs will have access to/be able to report this data
- 2021 CDC EHDI HSFS (*released in Fall 2022*) planned to include new questions around family-to-family support, based on interests from EHDI partners.
 - New fields Optional / not required
 - Similar process to previous updates to HSFS
- **Note:** Will not be included as part of patient-level (iEHDI) data (DD20-2006)

Family-to-Family Support: Next Steps



- EHDl Data Committee met February 2022.
 - General consensus this information is important.
 - Committee discussed feasibility on collecting this information.
- A workgroup (consisting of state EHDl programs, Hands & Voices, HRSA) has been formed to discuss new questions to add to the HSFS.
 - First meeting March 22 (**tentative**)
 - Goal: finalize questions by June 2022

Intervention & Outcomes: Background



- CDC EHDI Program (National Center on Birth Defects and Developmental Disabilities / Disability and Health Promotion Branch) interested in and supports efforts to:
 - Assess outcomes of children who are as deaf or hard of hearing (DHH)
- Part of CDC EHDI's work includes collaborating with partners to better understand the effects of intervention and outcomes among children who are D/HH.
- In 2020 CDC EHDI began a new initiative to establish an Outcomes and Developmental Data Assistance Center for EHDI (**ODDACE**) Programs (DD20-2005)
 - University of Colorado-Boulder
 - Project Director: Allison Sedey, Ph.D., CCC-SLP, CCC-A

Outcomes and Developmental Data Assistance Center for EHDI (ODDACE) Logic Model

STRATEGIES/ACTIVITIES

Surveillance

Identification, standardization and collection of intervention and outcome data

Collaboration

Engaging and aligning partners

Capacity Development

Building the capacity to gather standardized intervention and outcome data

Data Analysis

Analyzing intervention and outcome data across states to assess provision of services and outcomes

Translate and Disseminate Information

Using data to inform decisions and practices



LONG TERM OUTCOMES

- **Strategic partners have accurate and standardized surveillance data on the outcomes of children who are D/HH**
- **Increased understanding of factors impacting the outcomes of children who are D/HH at the state and national level**
- Strategic partners use surveillance data to inform evidence-based intervention policies and practices that meet the needs of children who are D/HH
- Implementation of evidence-based intervention strategies to help reduce morbidity during early childhood

Notes

D/HH: Deaf or hard of hearing

Bold indicates outcomes that the awardees are accountable for during the project period.

ODDACE Project Priorities



- Support states in assessing outcomes
- Promote the use of a standard set of normed assessments
- Assist states in using results to inform intervention
- Create a national outcomes database
- Determine program, child, and family characteristics related to successful outcomes

Data Collection and Feedback



- Data from partner intervention programs (*for each child*)
 - Demographic form
 - Developmental Assessment of Young Children (DAYC-2) and MacArthur
 - Additional optional assessments available
 - Hearing test results or signed release of audiology information form

- ODDACE Activities
 - Assessments are scored
 - Individual child-level report of results generated and sent to interventionist
 - Annual report sent to program director (summarizes results of program)

ODDACE Progress: Sept. 2020 – Present



Surveillance

- 11 programs submitting data to ODDACE, and 3 additional are “onboard”
- Received 1399 assessments as of March 3rd, 2022
- Developing a database and tools to ease the reporting burdens on participating program providers and improve data quality

Collaboration

- Feb. 1, 2020, expert panel and stakeholder meeting
 - Participants: CDC EHDI and ODDACE leadership, Federal partners, State EHDI and Part C programs, National Organizations
 - Expanding collaboration into geographic regions and communities not already served by ODDACE
 - Strengthening partnerships between Part C and State EHDI programs
 - Balancing surveillance and research

Capacity Development

- Conduct a survey to assess current barriers and challenges affecting participation by programs and families.

Data Analysis

- Received the 1st Quarterly Data Report with descriptive statistics

Translate and Disseminate

- ODDACE website (www.colorado.edu/center/oddace.com) to share information and publications

EHDI Outcomes Committee: Background



- Formed in April 2016 with first meeting in May 2016
- Partnership between CDC and Early Childhood Technical Assistance (ECTA) Center at UNC Chapel Hill with the addition of the DaSy Center in 2018
- Current members:
 - EHDI state coordinators (approx. 20)
 - State Part C coordinators (approx. 10)
 - CDC and HRSA staff
 - ECTA and DaSy staff
 - NCHAM, Hands & Voices and the FL3 Center representatives, ODDACE, researchers

Original Goals of the Committee



- Make recommendations to CDC EHDI program about potential outcomes data EHDI programs could collect, including from Early Intervention/Part C programs
- Identify challenges with collecting EI/Part C data for EHDI reporting
- Review and make recommendations about modifications, additions and/or recommendations to the functional standards related to EI

Challenges Identified: 2016 -2018*



- Parental consent and data sharing
- EI Data Systems vary from state-to-state,
 - Types of data collected and how data are stored
- Need for increased communication between federal agencies at top levels (OSEP, HRSA, and CDC)
- Need for greater understanding of EHDI and EI programs about each other's program
 - Especially at the provider level

*Adapted from February 2022 ECTAC presentation

Outcomes Committee Work: 2021 - 2022



- Two workgroups formed
 - Group 1: Develop guidance from state EHDI and Part C to local agencies regarding the importance of data sharing,
 - Why it is needed and strategies for sharing data
 - <https://ectacenter.org/topics/earlyid/ehdidata.asp>
 - Group 2: Develop a data sharing agreement checklist and a data sharing agreement template

- Other work
 - Collect data sharing agreements and with consent of states, provide a central location to post these agreements
 - Provide encore presentations



Thank You & Questions