

NE-EHDI Update for March 2017 Deaf/HH Stakeholder Meeting

The NE-EHDI 2015 data reported at the November, 2016 Deaf/HH Stakeholder Meeting was a point in time report. The following data is updated as of March, 2017:

There were 27,124 births in NE in 2015

- 26,862 passed the screening or diagnostic test (99% of births)
- 108 Expired (inpatient or outpatient)
- 61 were Diagnosed as Deaf or Hard of Hearing
 - 4 of 61 (7%) were late onset (due to illness)
 - 44 of 61 (72%) enrolled in Nebraska early intervention
 - (others not eligible, refused, not living in Nebraska)
- 42 Parents Refused screening and/or diagnostic testing
- 18 Parents were Unresponsive (did not complete protocol after communication with NE-EHDI staff)
- 13 Lost (no response to NE-EHDI letters and phone calls)
- 11 Moved out of Nebraska
- 7 Are in follow-up (still waiting for final screening or final diagnostic testing)
- 2 Other (medically fragile)

Of the 1,026 infants followed by the NE-EHDI Program for 2015 births:

- **Over 90% of these infants have completed the recommended follow-up of outpatient screening/diagnostic testing.**
- **Approximately 70% of those identified as Deaf/HOH have been enrolled in Part-C early intervention services (EDN) within six months of birth (if living in Nebraska and verified).**

There were 27,111 births in NE in 2016

- 26,816 passed the screening or diagnostic test (99% of births)
- 121 Expired (inpatient or outpatient)
- 63 Diagnosed as Deaf or Hard of Hearing
 - 4 of 63 (6%) were late onset (due to illness)
 - 41 of 63 (65%) enrolled in Nebraska early intervention
 - 10 of 63 (16%) referred and expected to enroll
 - 12 of 63 (19%) others not eligible, refusing, not living in Nebraska
- 30 Parents Refused screening and/or diagnostic testing
- 21 Parents were Unresponsive (did not complete protocol after communication with NE-EHDI staff)
- 2 Lost (no response to NE-EHDI letters and phone calls)
- 8 Moved out of Nebraska
- 50 Are in follow-up (still waiting for final screening or final diagnostic testing)

The above 2016 births numbers and percentages are preliminary.

All birthing hospitals in Nebraska conducted newborn hearing screening as a standard of care for 2015 & 2016 births.

Nebraska Hearing 1-3-6 Statistics 2013-2014-2015			
	2013	2014	2015*
Screening within 1 month	98%	98%	98%
Diagnostic Evaluation within 3 months	39%	58%	44%
Early Intervention within 6 months (referred, eligible & accepting)	70%	83%	71%

*2015 percentages are preliminary

NE-EHDI is required to report stats to CDC annually.

- The last stats reported to CDC are 2014 submitted May, 2016.
- CDC is changing the format for reporting the 2015 stats. CDC anticipates information will be sent to states and information will be due April or May, 2017.
- The 2014 NE-EHDI stats compared to National stats were shared at the November, 2016 meeting. The 2015 NE-EHDI stats compared to National stats will be shared after all states have reported their 2015 data to CDC.

NE-EHDI currently receives Federal funding from Health Resources and Services Administration (HRSA) and Centers for Disease Control and Prevention (CDC). We receive NO state funds.

- **HRSA current funding cycle is April 1, 2016 – March 31, 2017** (the last year of this grant cycle.)
 - **NE-EHDI submitted a competitive grant application to HRSA Oct 7, 2016.**
 - the new funding cycle is for 3 years (April 1, 2017 – March 31, 2020).
 - The full amount of funding for \$250,000 annually was requested.
 - **Funding Goals:** Increasing health professionals’ engagement within and knowledge of the EHDI system. Improving access to Early Intervention services and language acquisition. Improving family engagement, partnership, and leadership within the EHDI programs.
 - The requirements changed with this new grant. 25% of the funding is required to be allocated to family support organizations or organizations that provide family support.
 - EHDI will be collaborating more with Hands and Voices/GBYS Program to help with follow-up and assisting families with developing care coordination plans through a patient/family –centered medical home.
 - EHDI has only begun conversations with PTI-NE to assist with developing training and protocol for care coordination plans. These will be shared

through our website with medical professionals, family support organizations and EI providers to assist families when their child is diagnosed as deaf or hard of hearing.

- **CDC current funding cycle is July 1, 2016 – June 30, 2017** (the last year of this grant cycle.)
 - **NE-EHDI submitted a competitive application to CDC March 21, 2017.**
 - The new funding cycle is for 3 years (July 1, 2017 – June 30, 2020).
 - The full amount of core funding for \$150,000 annually was requested.
 - Funding Goal: Improve the documentation of timely follow-up diagnostic testing and early intervention services, in order to support the early identification of D/HH infants and help address potential developmental delays.
 - **CDC requirements involve using five types of strategies:**
 - 1) **Surveillance to implement a complete EHDI-IS**

Work plan example: Improving on capturing timely data (and strive to categorize the reason for delayed Dx (diagnostic) & EI events) by having NE-EHDI staff enter details into ERS (NE-EHDI data collection system) on why there is a delay for Dx or EI.
 - 2) **Training and support to provide training and technical assistance to address the needs of state partners involved in the EHDI reporting processes.**

Work plan example: Annual meeting with all audiology clinics to discuss reporting options.
 - 3) **Partnership to promote and support coordination and collaboration around capturing data.**

Work plan example: Meetings with audiology clinics and EDN staff to discuss the importance of timely reporting and ways to improve timeliness of reporting & ways to improve the timeliness of Dx/EI events.
 - 4) **Communication and dissemination to support targeted dissemination of data and information among stakeholders.**

Work plan example: NE-EHDI creates reports for CDC, annual report for legislature, reports for advisory committee and discussion on challenges, QA reports for hospitals, new QA reports for EDN staff and audiology clinics. NE-EHDI is open to other ideas?
 - 5) **Monitoring, analysis and evaluation to maintain data quality and guide programmatic improvement.**

Work plan example: Monthly NE-EHDI staff meetings for evaluation of system, data capture, delayed cases and ways to influence timeliness of reporting and events happening in a timely manner; Evaluation of Tele-Audiology project. Also, will be discussing with Advisory Committee.