REDUCING LOST TO FOLLOW UP NUMBERS

STILL A KEY COMPONENT OF SUCCESSFUL EHDI PROGRAMS

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Nebraska Early Hearing Detection & Intervention Program

ABSTRACT

Universal Newborn Hearing Screening (UNHS) identifies childhood hearing loss at an early age and assists in timely early intervention, which has a significant impact on language development. Research shows that children with congenital hearing loss who receive early intervention prior to six months of age have better speech, language and educational outcomes than those who are identified later in life. In addition, early detection and early intervention saves special education (SPED) dollars. According to information published in the January 30, 2004 issue of Morbidity and Mortality Weekly, SPED costs for a child with unidentified hearing loss who does not receive early intervention will cost schools an additional $420,000 per child by the time that child graduates high school. Thus, timely follow up is essential for infants who do not pass their newborn hearing screening.

From 2000-2016, the Health Resources & Services Administration (HRSA) grant goals focused on building EHDI infrastructure within state health departments to ensure babies are screened according to the Joint Committee on Infant Hearing (JCIH) 1-3-6 guidelines. As a part of that infrastructure architecture, HRSA focused on reducing Lost to Follow-up (LFU) numbers after the child does not pass their newborn hearing screening. Although the focus of the HRSA grant has shifted to family support and early intervention, reducing LFU numbers is still a key component for EHDI programs. If the screening and diagnostic steps in the follow-up process are not completed, the subsequent family support and early intervention steps will not happen.

In 2014, the CDC reported that while 97.9% of infants born receive an inpatient hearing screening, only 64.6% are known to have the recommended outpatient testing (screening or evaluation), and 34.4% are “lost” to the system. (2014 CDC EHDI Hearing Screening & Follow-up Survey (HSFS)). Based on CDC probability model calculations, approximately 3,600 in this "lost" group could have permanent hearing loss, and likely will not receive proper intervention before they reach school age.

Nebraska’s LFU numbers have been significantly reduced from 41.1% in 2010 (2010 CDC EHDI Hearing Screening & Follow-up Survey (HSFS)) to 9% in 2014 (2014 CDC EHDI Hearing Screening & Follow-up Survey (HSFS)). Not only has the NE-EHDI LFU numbers decreased dramatically, the 2014 numbers are significantly lower than the 2014 national average of 34.4%.

The objective of this poster is to detail simple and replicable methods used by NE-EHDI to reduce LFU numbers.

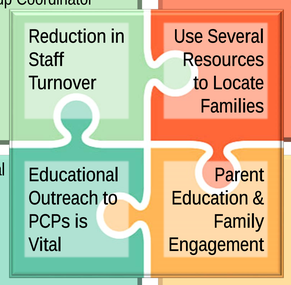
METHODS

One of the key components in being able to reduce LFU numbers has been stable and consistent staff for the Follow-up Coordinator position. Prior to 2011, the Follow-up Coordinator role was filled with a temporary, part-time Staff Assistant position. This resulted in high staff turnover and high LFU numbers.

- In April 2011, the Follow-up Coordinator position was reclassified as a full-time temporary position.
- In May 2012, the Follow-up Coordinator position was reclassified at the temporary Community Health Educator pay grade.
- In September 2013, the Follow-up Coordinator position was reclassified as a permanent position.
- In December 2016, the Follow-up Coordinator position was reclassified at the Community Health Educator Senior pay grade.
- The same person has been in the role of Follow-up Coordinator since April 2011.

Many times a case is LFU because the parents contact information was not provided to EHDI by the hospital, the family has moved, changed phone numbers, and/or Primary Care Providers (PCPs). NE-EHDI uses a number of different databases and resources to find current contact information. Resources include:

- Nebraska Medicaid Database
- Nebraska Economic Assistance Database
- Nebraska Health Information Initiative (NeHII)
- Perkin Elmer Genetics Dried Blood Spot Database
- Contacts within Child & Family Services
- Early Development Network
- Connection with other states within the EHDI system.
- Looking for information on social media like Facebook.



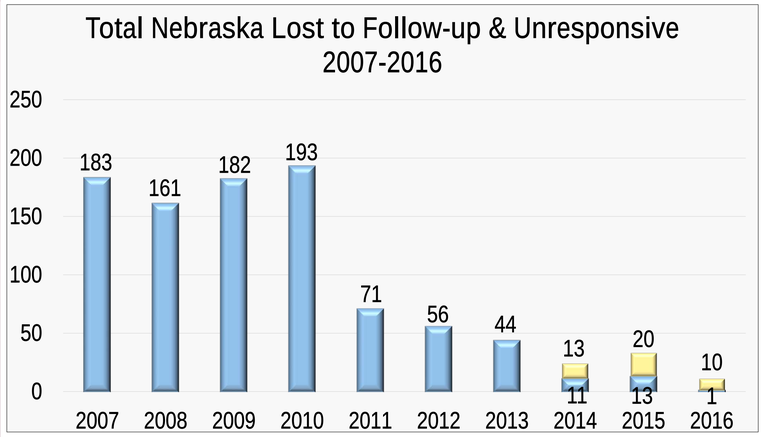
A survey conducted by the National Center for Hearing Assessment And Management (NCHAM) in 2005 and again in 2012 showed that, over the course of seven years, physicians’ confidence in their knowledge related to early hearing detection and intervention increased, while their competence in understanding the process decreased. To assist physicians and improve educational outreach, NE-EHDI has taken these steps:

- Written protocols regarding JCIH Guidelines have been provided to hospitals, and on-going training is encouraged.
- Physicians’ are contacted frequently regarding specific cases, and assistance in coordinating care is offered.
- Information about specific cases where JCIH guidelines were not followed is shared with physicians for the purpose of educational outreach.

Phone calls to parents start shortly after inpatient refer results are reported to NE-EHDI. Frequent reminder calls are made until the parents follow through with appropriate next steps. Education about the importance of timely follow up is stressed each time a parent is contacted.

- Two letters are mailed to the parents.
- A certified “LOST” letter is sent to the parents as a final request.
- Referrals to EI are made prior to identification if the family needs additional resources or in person education.
- A referral to Child Protective Services is made if there are risk factors and the parents are not following up.
- Guide By Your Side is offered early in the process so parents have access to support.

RESULTS



DOB Year	Total Births	Number Tracked by NE-EHDI	Percent LFU/LTD
2007*	26,893	1048	50.7%
2008*	26,904	1226	40.2%
2009*	27,013	1434	33.3%
2010*	26,039	1343	41.1%
2011*	25,915	1300	20.0%
2012*	26,129	1007	28.3%
2013*	25,256	958	26.2%
2014*	26,957	904	9.0%
2015*	27,121	1025	13.7%
2016#	27,116	1027	5.6%

*Per CDC EHDI Dashboard
#Preliminary Data

For information on how this data is calculated visit https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

ANALYSIS - LOST VS. UNRESPONSIVE

- In 2014, the CDC began allowing “Unresponsive” as a sub-category of the LFU group. Cases can be classified as “Unresponsive” when documented two-way correspondence has occurred between EHDI and the parents, or the PCP and the parents.
  - This change more accurately represents the status of cases where aggressive efforts are made to follow-up, but the parents are non-compliant.
- Although classifying some cases as “Unresponsive” has reduced the rate of children who are classified LFU, there are still many children in the LFU/unresponsive category, as shown on the chart above. As a result, they are not identified early and/or enrolled in early intervention on time, which is the whole purpose of the EHDI process. These children are still “lost”.
- The number of cases in “Unresponsive” status leads to many more questions:
  - Why are parents hesitant or unmotivated to follow up on a failed hearing screening?
  - How are parents educated about the newborn hearing screening in the hospital, by their PCP, ENT, and/or Audiologist?

A PARENTS STORY-SHE COULD HAVE BEEN LOST

Photos by Craig Chandler/University of Nebraska-Lincoln University Communications

- When Evie referred on her UNHS, her parents were told by the nursery nurses “this happens a lot, it’s probably just fluid.”
- Evie’s PCP assured her mother that Evie could hear, it was “just fluid in her ears that will eventually drain out” that kept her from passing the hearing screening.
- After several months of middle ear management, Evie had tubes placed. The ENT assured Evie’s parents that she could hear, and the tubes would resolve the hearing issues.
- Frequent letters and phone calls from the NE-EHDI program finally motivated Evie’s mom to go to a pediatric audiologist for a diagnostic ABR.
- Evie was identified with mild-moderate permanent sensorineural hearing loss at nine months of age.

Scan here to learn more about Evie’s story:

CONCLUSIONS & SUGGESTIONS

- Reducing the rate of children who are LFU is still an important goal for EHDI programs.
- Frequent outreach from NE-EHDI to both parents and PCPs is a key component of reducing LFU numbers.
- Family engagement is important in every part of the EHDI process, from timely screening, to identification, and enrollment in early intervention services.
- Skilled professionals who are well versed about infant hearing help to reduce LFU numbers. Parents rely on the professionals involved in the EHDI process to help them understand important next steps, and motivate them to follow up. Ideally, each state would have a “center of excellence” in childhood deafness as a resource to help families connect with all the necessary professionals.
- PCPs and ENTs who are responsible for care coordination need more information about the EHDI process and childhood deafness.
- In states where access to care is an issue, statewide teleaudiology locations would help to ensure that all children have access to the same quality of care.
- Nationwide efforts at the Federal level are needed to raise awareness about the prevalence of childhood deafness, the importance of early identification and early intervention, to dispel misconceptions about infant hearing, and to educate families.

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