

## DATA MANAGEMENT SOFTWARE AND SERVICES: THE IMPACT OF SUCCESSFUL TRACKING AND FOLLOW-UP

The adoption of universal newborn hearing screening over the past two decades has dramatically increased the number of infants tested for hearing loss prior to hospital discharge. The continued success of Early Hearing Detection and Intervention (EHDI) programs depends on successful tracking and follow-up to ensure that babies referred from the hospital receive appropriate and timely diagnostic audiological assessment and early intervention services. The most challenging aspect of an EHDI program is keeping track of patients through the screening, referral, and diagnostic process. This aspect is most challenging due to inconsistent documentation, lack of communication and coordination among facilities and providers, and lack of data sharing.

### EHDI

In their 2007 Position Statement, the Joint Committee on Infant Hearing (JCIH) outlines that all infants should be screened no later than 1 month of age, those who do not pass screening should have a comprehensive audiological evaluation no later than 3 months of age, and infants with confirmed hearing loss should receive appropriate intervention at no later than 6 months of age (JCIH, 2007).

JCIH goes on to define the EHDI information infrastructure requirements needed to help meet this goal:

"States should implement data-management and tracking systems as part of an integrated child health information system to monitor the quality of EHDI services and provide recommendations for improving systems of care..."

Information systems should be designed and implemented to interface with electronic health charts and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels."  
(P.899-901)

EHDI systems should guarantee seamless transitions for infants and their families throughout the entire process, but currently many do not. The JCIH notes several breakdowns of EHDI programs: consistent system-wide problems including failure to communicate information to families in an understandable format at all stages of the EHDI process; lack of integrated state data management and tracking systems; and a shortage of facilities and personnel needed to provide follow-up for infants who are referred from newborn screening programs (JCIH, 2007). On a national level, EHDI programs are not meeting the JCIH quality indicator for confirmation of hearing loss which requires "90% of infants who fail initial screening and any subsequent rescreening

must complete a comprehensive audiological evaluation by 3 months of age" (JCIH, 2007). National EHDI program statistics are at 75.9%, falling far short of this 90% benchmark. (CDC, 2016).

### LOSS TO FOLLOW-UP

Despite the fact that approximately 98% of newborn infants have their hearing screened in the United States, almost 32% of infants who do not pass the initial screening do not have appropriate follow-up to either confirm the presence of a hearing loss and/or initiate appropriate early intervention services (CDC, 2016). The CDC's definition of lost to follow-up is infants referred for testing who do not receive intervention and cannot be contacted by the EHDI program (Gaffney, Green, & Gaffney, 2010). The impact of loss to follow-up not only affects the newborn and their families, but also has a significant long-term effect on public health.

Early identification of hearing loss in newborns supports timely development of speech and language skills during the first two years of life. Congenital and early onset childhood deafness or hearing impairment may have a lifelong effect on the development of the auditory neuromaturation pathway of children if appropriate and optimal interventions are not provided within the critical period of central auditory pathway development (World Health Organization, 2009). Left unidentified, hearing loss can negatively impact speech and language development, academic achievement, and social/emotional development (American-Speech- Language-Hearing Association, 2005). Early identification and treatment helps ensure that newborns identified with hearing loss are able to receive timely and appropriate treatment which allows for appropriate developmental growth (American Speech Language Hearing Association, 2005).

According to the CDC, an average lifetime cost for a person with hearing loss is \$417,000. This lifetime cost includes both direct and indirect costs. Direct costs account for 36% (\$150,120) of the total lifetime cost and include medical expenses such as doctor visits, medications, and hospital stays, as well as home modifications and special education (CDC, 2004). Indirect costs account for 63% (\$262,710) of the total and include the value of lost or reduced wages when a person cannot work or is limited in the amount or type of work he or she can do (CDC, 2004). These estimates do not include additional expenses, such as hospital outpatient visits, sign language interpreters, and family out-of-pocket expenses (CDC, 2004).

## ECONOMIC COSTS ASSOCIATED WITH HEARING LOSS\*

TEXAS					
	2011	2012	2013	2014	2015
Infants identified with hearing loss	408	412	262	461	491
Loss to Follow-up Rate	74.4%	76.6%	61.4%	54.7%	53.7%
Babies lost to follow-up	3,818	3,776	3,208	3,262	3,059
Lifetime Direct Cost	\$573 M	\$567 M	\$482 M	\$490 M	\$459 M
Lifetime Indirect Cost	\$1,003 M	\$992 M	\$843 M	\$857 M	\$804 M
<b>Total Cost</b>	<b>\$1,576 M</b>	<b>\$1,559 M</b>	<b>\$1,324 M</b>	<b>\$1,347 M</b>	<b>\$1,263 M</b>
CALIFORNIA					
	2011	2012	2013	2014	2015
Infants identified with hearing loss	894	945	909	995	1,106
Loss to Follow-up Rate	8.4%	15.7%	16.3%	8.8%	5.0%
Babies lost to follow-up	231	436	458	247	143
Lifetime Direct Cost	\$35 M	\$65 M	\$69 M	\$37 M	\$21 M
Lifetime Indirect Cost	\$61 M	\$115 M	\$120 M	\$65 M	\$38 M
<b>Total Cost</b>	<b>\$95 M</b>	<b>\$180 M</b>	<b>\$189 M</b>	<b>\$102 M</b>	<b>\$59 M</b>
TOTAL COST SAVINGS FOR CALIFORNIA VS. TEXAS					
	2011	2012	2013	2014	2015
	\$1,481 M	\$1,379 M	\$1,135 M	\$1,245 M	\$1,204 M

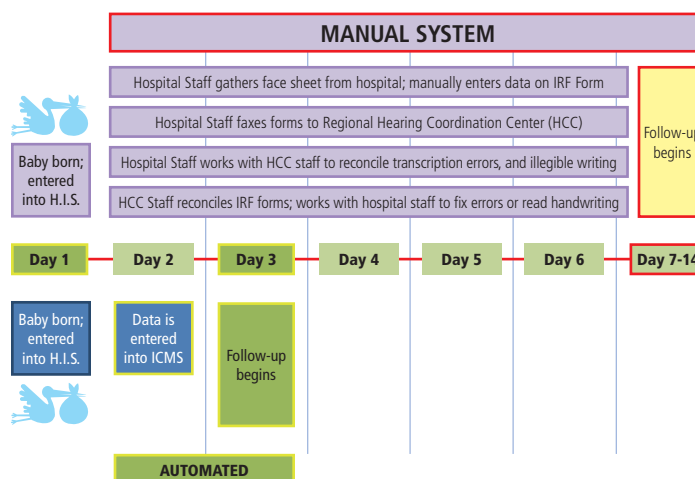
\*CDC Annual Data Early Hearing Detection and Intervention (EHDI) Program  
All numbers in \$Millions

As seen in the chart above, the costs associated with infants lost to follow-up can be very high. State EHDI programs selection of data management software and services plays an important role in the tracking and follow-up of newborns as well as greatly impacts the total lifetime cost to the state. If newborns do not receive the appropriate timely audiological assessment and intervention after a referred hearing screen, their lifetime societal cost will be even higher due to the delayed diagnosis and treatment (CDC, 2004).

## DATA MANAGEMENT SOFTWARE AND SERVICES: IMPACT ON LOSS TO FOLLOW-UP

Far too often, EHDI is added as an afterthought to a facility's existing data management system, with little understanding of the unique requirements for the tracking and follow-up required by an effective Universal Newborn Hearing Screening program. Implementing an effective data management system involves much more than just building or purchasing data management software and distributing it to users. The system should be evaluated to ensure complete demographic data, hospital specific data, and state-reporting data requirements are met as well as maintaining federally mandated HIPAA/FERPA compliance.

The CDC endorses the recommendations made by the 2015 National Early Hearing Detection and Intervention Information System (EHDI-IS) Functional Standard Working Group (FSWG) on the technical functional requirements for a complete EHDI-IS. The group not only provides 8 programmatic goals, but specific standards that address each of the programmatic goals. These standards are divided into the following categories: mandatory requirements to be followed/ implemented; elective recommended actions; and additional optional actions (CDC, 2015). It is essential that the goals and standards are fully evaluated when developing a case management system. Neometrics' web-based Case Management System (iCMS) meets all data and functional requirements. Neometrics' iCMS is a software application for tracking and managing the newborn screening follow-up process. The advantage of iCMS is that it automates the daily workflow of follow-up staff, and provides a mechanism for recording follow-up activities. iCMS enables secure tracking of infants from point of entry through receipt of services and eventual case closure. iCMS allows data imports from a variety of hearing screening devices and integration with various information systems through its advanced electronic data transfer capabilities. iCMS standardizes data collection across all entities and facilitates communication within hospital associations.



Neometrics iCMS not only meets the mandatory requirements of the FSWG, but also meets the elective optional actions, which include the ability to:

- make referrals for recommended follow-up services
- receive and document information about referrals and/or recommendations made following an audiological diagnostic evaluation
- notify parents and healthcare providers of infants who are in need of follow-up service
- generate, present, and transmit a standard-based hearing plan of care document to guide follow-up practices in accordance with scope of practice, organizational policy and jurisdictional law
- receive and document information about risk factors of infant hearing loss at the time of newborn hearing screening
- regularly evaluate incoming and existing hearing screening and diagnostic information to continually refine, modify and efficiently identify late onset, progressive and acquired hearing loss
- record notes and phone interactions with the public (parents, providers, hospitals) within each child's file (CDC, 2015)

In addition to the data management software solution, Neometrics also has the ability to provide the personnel to manage hearing case management activities for all screened infants identified with hearing loss. By acting as the Hearing Management Services for the newborn hearing screening program, Neometrics will be responsible for the following key functions:

1. Recommend initial certification approval of new hospitals to participate in the Newborn Hearing Screening Program (NHSP) and recertification approval of current participating hospitals at the end of the previously approved certification period.
2. Provide technical assistance and consultation to all hospitals with licensed perinatal services.
3. Track and monitor infant screening, re-screening, diagnostic, and intervention services.
4. Assess service needs and provide referrals for families of infants with hearing loss.
5. Perform data collection, processing, and analysis.
6. Perform quality assurance activities.

By effectively meeting all of the goals, standards, and key functions noted above, Neometrics reduces the problem of loss to follow-up and the financial and societal impact that it has on the state.

## OPPORTUNITIES FOR IMPROVEMENT

EHDI programs seek to improve tracking and follow-up through timely diagnostic audiological and early intervention services. Early identification and treatment ensures that newborns identified with hearing loss can receive timely and appropriate treatment which allows for appropriate developmental growth. Data management software is essential in supporting EHDI programs to fully meet JCIH quality indicators. The software should be evaluated to ensure basic data, hospital specific data, and state-reporting data requirements are met and that the software fully meets the goals and recommendations of the CDC and JCIH.

## REFERENCES

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