

# Iowa EHDI News

Your Sound Source for Early Hearing Detection & Intervention Information

Winter 2015

## The EHDI World

- The Early Hearing Detection and Intervention (EHDI), Dried Blood Spot and Critical Congenital Heart Disease (CCHD) programs are working to integrate, where possible. Collectively they will be called Iowa's Newborn Screening Program. Integration includes the development of a comprehensive integrated data system and a joint brochure. With this change, program personnel hope to see an increase in data completion and accuracy in the integrated surveillance system. This change means tokens will no longer be needed to access the database; however two-factor authentication will still be in existence. More information will be provided at a later date on returning tokens and ordering the newborn screening programs brochure.
- The EHDI program staff completed 52 referrals to two pilot WIC agencies for children in need of a hearing rescreen through a pilot program with WIC. The WIC agencies work with families attending their clinics to assist in scheduling a follow up hearing screen for their children. EHDI and WIC continue to collaborate in this pilot to determine if this partnership decreases the numbers of children lost to follow up/documentation and improves timely follow up.
- A short video has been developed for parents to introduce them to newborn hearing screening and the importance of follow up. The video is about two and a half minutes long and it's a perfect educational tool for parents. The video link is available on the EHDI website at <http://idph.iowa.gov/ehdi/families>.
- The EHDI program staff is exploring the use of texting as a way to communicate with families during follow up. The goal is to reach parents who may not be available by phone or more inclined to respond via text message. Other states have implemented similar programs and received positive results. Texting is scheduled to begin in March 2016.
- The Iowa Department of Public Health rolled out a new website on October 19, 2015 following a request by the governor for all state websites to use the same design for a similar look and ease of use by the general public. Please save the new EHDI website, <http://idph.iowa.gov/ehdi> to your favorites. The structure of the website is similar to the old website as there are pages developed for families and pages developed for professionals. You will find a navigation bar on the left side of the page to assist you in locating forms, educational materials, best practices and others. If you cannot find something in particular, please contact one of the EHDI staff for assistance. Additionally, EHDI staff is working to add more resources and make the site more user friendly so make sure you check back from time to time to see the updates.
- Parent surveys will be mailed in February 2016 to a random sample of parents (approximately 2000) whose children were born in 2015. The surveys inquire about their experiences and knowledge of newborn hearing screening and follow up. The feedback the program receives will be used to improve future programming and guide policy and decision making for newborn hearing screening and follow-up services for other families in Iowa.
- The Quarterly Reports are being updated this upcoming quarter. The screening outcome "Outpatient screened by 1 month" will be removed from future reports as children bypassing the outpatient screening and going directly to diagnostic assessment were not being read by the system as being screened in a timely manner. Contact [kristy.johnson@idph.iowa.gov](mailto:kristy.johnson@idph.iowa.gov) with questions on the Quarterly Reports.

## What's Inside...

- 2 Upcoming Trainings & Loaner Equipment
- 3 Exploring Parental Perception of the Current Newborn Hearing Screening Program: Literature Review
- 4 & 5 A Parent's Perspective
- 6 & 7 QI Corner & Best Practices Tip
- 8 Sound Bites & Ordering Brochures
- 9 Contact Information



### Upcoming trainings:

Introducing NCHAM's new free online Tele-intervention Learning Courses!

Tele-Intervention (TI) - the provision of early intervention services via teleconferencing technology - has become increasingly popular as a method to increase access to services for families of children with special needs, especially families of children who are deaf or hard of hearing. To support early intervention programs that are interested in implementing TI, three online introductory level courses are available: one for administrators, one for providers, and one for families. These courses are offered free of charge, thanks to funding from the Daniels Fund. See these courses at [www.ti101.org](http://www.ti101.org)

## LOANER EQUIPMENT

Don't miss screening an infant because of broken equipment. If you are having problems with your hearing screening equipment, the EHDI program has a limited number of loaner screening OAE units available for hospitals to use while their screening equipment is being repaired.

NEW ~ The EHDI program has an AABR unit available for loan. There is no charge for borrowing the equipment, other than using your own consumables for screening and the cost of shipment back to the EHDI program when you are done using the equipment.

For information about loaner units, please contact:

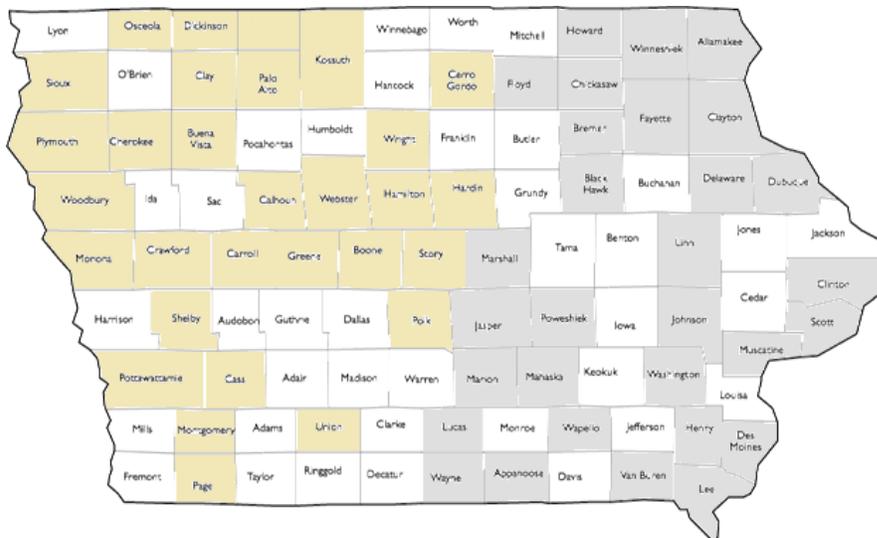
**Hearing Equipment Coordinator**.....(800) 272-7713

**Or your EHDI Audiology TA**

**Lenore Holte (Lead Pediatric Audiologist)**.....(319) 356-1168

**Emily Andrews (providing support to the eastern half of Iowa)**.....(319) 384-6894

**Bill Helms (providing support to the western half of Iowa)**.....(515) 450-1132



# Exploring Parental Perception of the Current Newborn Hearing Screening Program: A Literature Review

By: *Brittany James, University of Iowa*

Much attention has been paid in the last 20 years to the marked speech, language, and educational gains attained through early detection of hearing loss and provision of intervention services. Research efforts in this area were paramount to the acceptance and implementation of universal newborn hearing screening (UNHS) programs and early intervention services for children with hearing impairment. Now that ample evidence has been attained regarding speech and language development associated with such programs, we must focus our attention on the parents and families affected by these measures. Particularly, as practitioners and proponents for newborn hearing screening programs, we must ensure that the psychosocial and emotional effects created by UNHS programs do not outweigh the potential speech and language benefits afforded by early detection and intervention.

More than ever, it is important to ensure parental satisfaction with services provided as the United States is slowly shifting from a fee-for-service reimbursement approach to a value-based reimbursement approach. Insurance companies are beginning to evaluate patient outcome measures, both objective and subjective, post medical intervention to gauge the monetary worth of the service (Porter, 2006). As such, continued support of EHDI programs and national legislation may soon be affected by outcome measures pertaining to parental experience with early detection and intervention. As an added benefit, parental report may provide valuable insight in how to adjust practices to better serve the communicative, social, academic, and vocational needs of children with hearing impairment and their families while also proving the worth of the system to third party payers (JCIH 2007).

A review of the relatively recent and relevant literature on parent perceptions and experience with the UNHS program was performed to assess current pitfalls and successes of the program. The overall aim of this thesis was to provide strategies for improvement to better serve families of children with hearing impairment.

Through evaluation of these parental experiences with the Universal Newborn Hearing Screening Program, a few key issues were illuminated, the biggest of which is inadequate professional communication (Hardonk et al., 2010; Luterman, 1999; Russ et al., 2004; Tattersall & Young, 2006; Yoshinaga-Itano, 2014). Professional communication has also been shown to be the biggest predictor of parental satisfaction with the UNHS program (Tattersall & Young, 2006). Arguably, the other issues illuminated through the literature search also stem from professional communication issues. Standardizing communication between providers interacting with these families, particularly physicians, screeners, nurses, and audiologists, can improve the vast majority of provider-family interaction. Good professional communication is distinguished by sensitivity, empathy, explanation, and honesty (Tattersall & Young, 2006). There are resources and training available to institutions and professionals to help improve communication between providers and families; professionals must take the time and effort to utilize these resources to improve the experience with the UNHS program and the lives of the families that are served by it. Based on this literature review, quality improvements in the UNHS program can be obtained by the following:

1. Utilizing AABR more in single and double stage screening programs, thus reducing rate of referral
2. Providing the opportunity for parents to be present during testing (Magnusson & Hergils, 2000)
3. Improving professional communication by:
  - a. Immediately relaying screening results
  - b. Using standardized scripts when relaying results
  - c. Including training on communication best practices with an emphasis on communication of results in healthcare programs (especially nursing and audiology programs)
    - i. i.e. role-play to provide students with practice delivering results
4. Delineating of screening measures from diagnostic measures using educational materials sensitive to different levels of language and health literacy

References for article available upon request by contacting [tammy.ohollearn@idph.iowa.gov](mailto:tammy.ohollearn@idph.iowa.gov).

# A Parent's Perspective on...

...Improving care for Iowa babies

\* **EHDI staff interviewed a parent about her experiences with newborn hearing screening and follow up. Her son was diagnosed with hearing loss and she shared her experiences through their journey.**



hearing screening and follow up much like they talked about diabetes during my pregnancy. Newborn's hearing can be one of the topics that are brought up at one of the appointments with OB providers. It is best to provide education about newborn hearing screening in a progressive, repetitive way starting prenatally.

**Were contacts from the EHDI program about your child's newborn hearing screening helpful?**

I remember receiving a letter from the Department of Public Health when my baby was about 3 ½ months old. I did not listen to voicemails regularly although I do now know that the Department of Public Health tried to leave me voicemails to follow up on my child's newborn hearing screen. I understand that voicemails may contain important information and as a result, I now listen to voicemails regularly. Parents have different venues of communicating as some would like calls, letters or other ways. I think it is important to try different venues to communicate with parents as one may not fit all. I would have loved if I had received a text message back then as this is a good way of communication for me.

**Did your child's birth hospital verbally communicate your child's newborn hearing screening results? Did you receive the results in writing?**

I was not told at the hospital about the newborn hearing screening results. I followed up with the hospital after discharge for my baby being jaundiced and I did not receive anything at that time either. The nurses acted like everything was okay when we were at the hospital and did not share that my baby failed the hearing screen. My husband shared with me that he thinks he may have been told when the hospital did the screening in the middle of the night but he could not remember for sure. I do not think it is best for parents to be told about their baby's screening results in the middle of the night; rather, it would be best if the hospital staff to sit down with parents prior to discharge and explain the results and information given. I felt rushed out during discharge.

**Was information about newborn hearing screening shared during your pregnancy?**

My OB provider mentioned that there was going to be newborn testing that would take place although there were no educational materials provided. I wish the OB provider would have stressed the importance of newborn

## Can you talk about your experience with hearing follow up services?

My child's primary care provider (PCP) did not discuss the newborn hearing screenings at the well child checks. As I shared, the first time that I heard about my child not passing the newborn hearing screening was when I received a letter from the Department of Public Health when my child was about 3 ½ months old. About two weeks later, we took it upon ourselves to follow up with a local ENT. The ENT asked if my child's birth hospital provided a follow up appointment before being discharged and I shared that they had not. The ENT provider reported that is against what is recommended as families should leave the hospital with an appointment for a repeat hearing screen already scheduled. After the ENT appointment, my child was referred to an out of state audiology clinic because of where we live. We then had to wait until my child was old enough and weighed enough for sedation. This was the first time my child's hearing loss was diagnosed; at that time my child was 5 ½ months old. We returned to our local ENT clinic and filled out paperwork for funding for hearing aids through the Hearing Aids and Audiological Services funding. We were quoted and approved four weeks later. My child was fitted with hearing aids at 8 ½ months old.

## Was information about Early ACCESS (early intervention) discussed or given to you when your child's hearing loss was diagnosed?

The local ENT that screened my child briefly mentioned early intervention services but no actual information was given. The services that Early ACCESS could provide or how the services are offered through the AEA was not explained. I am familiar with the AEA and it would have been helpful to know this. No referral was made or written information given. It was not until we went to a pediatrician appointment when my son was 14 months old that Early ACCESS services were brought up. The pediatrician asked why was the AEA not coming to our house and at that time a referral was initiated. I felt that the responsibility of the referral was with the local ENT as we are more familiar with the local provider and the out of state provider could not tell us much about Iowa services. I remember the local ENT mentioning at one point in time Early ACCESS services but no tangible contact information was given or referral made. I feel that the responsibility of the Early ACCESS referral relies on the local service provider rather than the family having to track down their information and understand their services not knowing what is available.

## What ways do you think are best to reach out to parents?

Communication with the family is key. Don't assume someone else is telling the family or making the referrals. It is best if everyone involved had said it rather than assuming that someone else is doing it and the information not getting to the family. The first week of a baby's life is often overwhelming for families, however, it is crucial that families are receiving important information regarding newborn care such as the newborn hearing screening. I had to go to three ultrasounds during my pregnancy because my baby's kidneys were underdeveloped. At that time, I didn't think anything of it as it resolved itself. After my child was diagnosed with a hearing loss and I did research, I learned that the kidneys and hearing develops at the same time prenatally. This connection was never made for me. The OB provider never mentioned how other things besides my child's kidneys could be affected at this time. My OB provider should have communicated more information about how different areas develop at the same time and how they could be connected.

## Have family support programs of any kind been offered to your family?

No information about family support was given to our family by any of the service providers. I have not connected with Iowa Hands & Voices and have not seen the Iowa EHDI website.

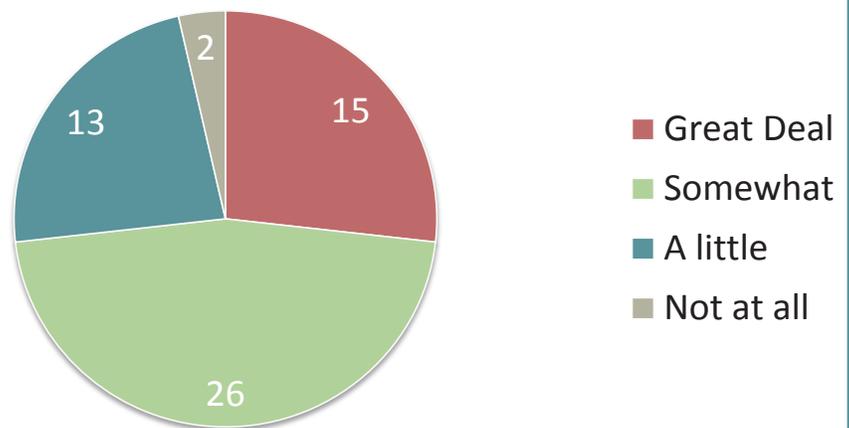
I had a question about singing time DVDs one day and I posted something on Facebook about it in a group that I am part of. Through there, I got connected with a mom who has a child with a similar hearing loss as mine. One of the things that I was inquiring about is how to explain hearing loss to a sibling. The mom that I connected with has been able to provide information and support and I have been able to meet other moms through this connection.

# Quality Improvement Corner

## Primary Care Provider (PCP) survey

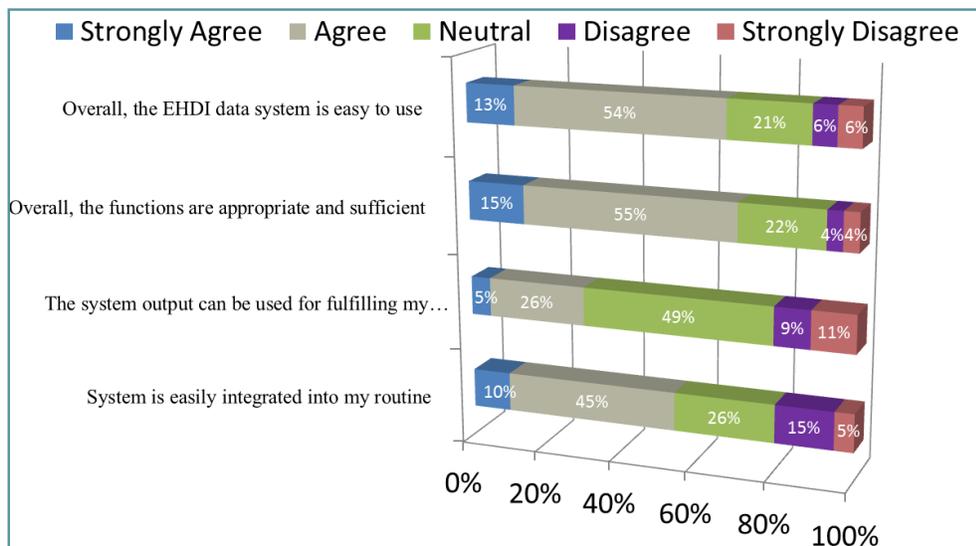
A survey was included in a mailing sent to PCP's along with a letter and informational materials. The survey included questions about the usefulness of the information sent and current practices for newborn hearing screening and follow up. The survey was sent to 1,911 PCP's with a return rate of 3 percent. Eighty-eight percent of the respondents said the information received was useful and 96 percent reported the information sent improved their understanding of newborn hearing screening and follow up. PCP's shared that they will typically refer the infant that missed or referred at the newborn hearing screening (73%) with many of them reporting that this is typically done by the birthing facility. When the outpatient screening was not already scheduled, PCP's reported they would help the family schedule an appointment (70%). An area of concern identified during review of the survey results was PCP's are only referring infants to a pediatric audiologist 45 percent of the time for infants that did not pass their outpatient hearing screen. The program will reach out to the Iowa EHDI AAP Chapter Champion for assistance in educating PCP's on best practices related to timely referrals for diagnostic assessments. Overall, the responses received in this survey were positive and similar to the responses received the last time that PCP's were surveyed (2011).

### Improved my understanding of newborn hearing screening and follow up



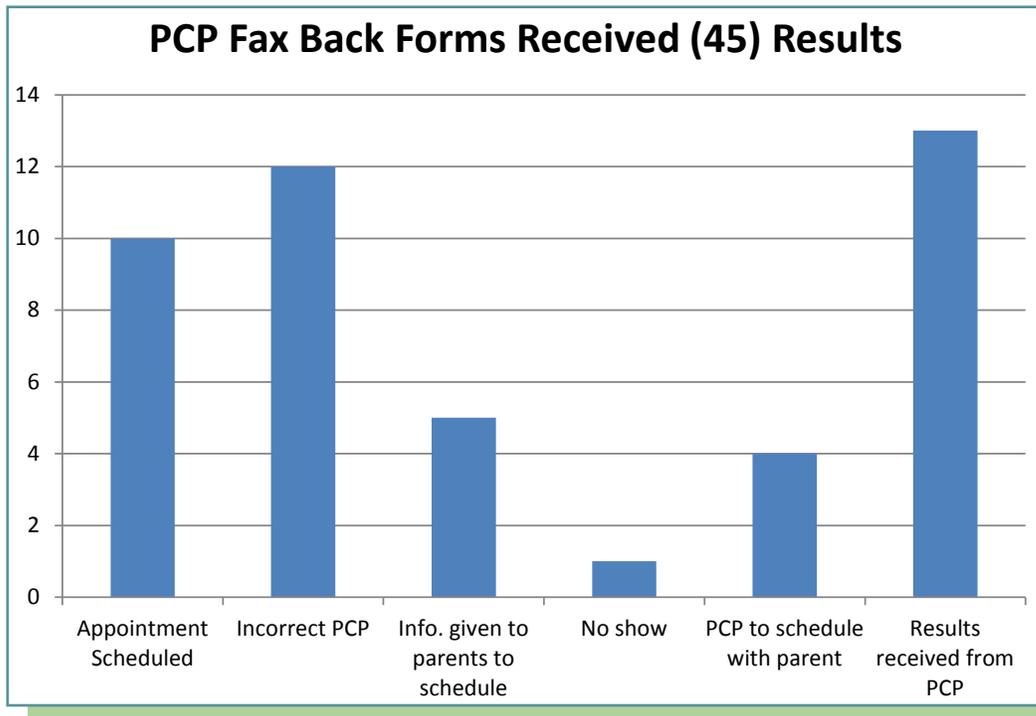
## EHDI Data System Survey Results

The EHDI program is currently in the process of integrating the EHDI database with two other newborn screening programs; dried blood spot and critical congenital heart disease. A survey was sent to current EHDI data system users asking about their experiences with the current system. There were a total of 111 respondents from: Birthing Hospitals (61%), Area Education Agencies (24%), ENT Office/Private Audiologist (10%), and "other" providers (5%). Most respondents reported they have used the database for over 3 years (70%), had 2 to 5 users that routinely used the EHDI data system (70%), manually enter demographic information (70%) and manually enter results (94%). Respondents also rated the easiest and hardest features of the database as well as provided suggestions for additional featured in the integrated database.



## Primary Care Provider (PCP) fax-back forms

PCP fax-back forms are designed to assist the EHDI program in providing timely follow up to babies who have referred in one or both ears by allowing providers to send/share information without the communication barriers associated with phone calls and emails. PCP fax-back forms have been sent in the past but the response rate was poor. Fax-back forms were revised and a pilot was initiated in 2015. There were a total of 120 faxes sent from May to September during the pilot project period; 59 forms (49 percent) were returned with responses, 23 forms (19 percent) found information during follow up/results entered after the PCP fax-back contact, 38 forms (32 percent) were not returned. Because of the success during the pilot, use of the fax-back forms for follow up has continued. The PCP fax-back forms will become a permanent part of the EHDI follow up staff protocol as it has proven to be as useful tool for communication between EHDI staff and PCP offices.



### BEST PRACTICES TIP

There are several ways to assure your OAE screening goes as smoothly as possible. One major way is to screen the baby in a quiet location while the baby is sleeping. A sleeping baby allows for the most accurate testing. Also, if possible, wait until the child is at least 24 hours old. Babies are often born with debris in their ear that may clog their canal and can prevent accurate responses. Waiting will allow the debris time to clear and may also help lower your refer rate.

# Sound Bites

*Updates from the EHDI Advisory Committee Meeting on July 9, 2015.*

## MEETING SUMMARY

- EHDI Administrative Rules are in the final stages of approval.
- CDC is looking into modifying or changing some of the reporting categories for EHDI programs.
- EHDI is looking into incorporating texting parents whose infants are in need of a hearing screen, rescreen and diagnostic assessment.
- EHDI will be rolling out a shared brochure with Dried Blood Spot and Critical Congenital Heart Disease programs.

For the complete meeting minutes, visit: <http://www.idph.iowa.gov/ehdi/committee>

## Next EHDI Advisory Committee Meeting:

April 7, 2015

Urbandale Public Library, Room A  
3520 86th St, Urbandale, IA 50322

**Please allow 48 hours' notice for accommodations.**

## Ordering Brochures:

The **NEW** brochures for EHDI will soon be ready for distribution. Remember – this brochure will be for all of newborn screening programs including Early Hearing Detection and Intervention, Newborn Dried Blood Spot and Critical Congenital Heart Disease. To order the current or upcoming brochures, contact the Healthy Families line at (800) 369-2229. For the current EHDI brochures, ask for publication IDPH131 (English) and IDPH 131s (Spanish).

## *We want to hear from you.*

We value your feedback and are here to answer any questions you may encounter throughout the hearing screening and follow-up process. Below is contact information for our dedicated staff. We look forward to hearing from you.

### **State EHDI Coordinator**

Tammy O'Hollearn  
Iowa Department of Public Health  
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### **EHDI Follow-Up/Family Support Coordinator**

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### **EHDI Program Assistant**

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