

Iowa EHDI News

Your Sound Source for Early Hearing Detection & Intervention Information

Spring 2015

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The Return of the Newsletter

After an extended leave of absence, our newsletter is back! Our lives have been busy, busy and in collaboration with many of you, we are continuing to serve children in Iowa by advocating for early screening and connecting them to the care that they need. We have lots to share with you about the happenings over the last year. A wealth of information, our latest edition of Iowa EHDI news brings you stories, tips and tricks of the trade, introductions, funding announcements and recognitions. Though the ability to create a newsletter depends on staffing, we are dedicated to staying connected to you. Our contact information is included to address questions that may arise and our website has a number of different resources and helpful links to assist you in navigating the world of EHDI. Thank you for your continued collaboration!

What have we been up to?

The EHDI team has been extremely busy over the last year. The program advanced data collection, evaluation, facilitated data sharing, increased quality assurance activities and used the results of various data analyses for decision-making related to programming and policy. The EHDI program continues to utilize quality improvement activities to influence change. Training was provided to birthing hospitals and Early Head Start/Parents as Teachers programs. The remaining private practice audiology clinics were trained on the use of eSP™ (EHDI database) and are using the data system to report hearing re-screens and diagnostic assessments. Tammy and Esha presented at the National EHDI conference in April 2014 on efforts to improve lost to follow up rates in Iowa. Dr. Sullivan, Dr. Holte and Tammy presented at the Iowa Academy of Family Physicians conference in November. IDPH EHDI partnered with Dr. Holte and a couple of audiology students to conduct research, specifically exploring the impact distance may have had on children needing a diagnostic assessment who ended up “lost to follow up.” [Learn more on pages 2 and 3.](#)



Iowa's Early Hearing Detection & Intervention Program

PROGRAM

With everything that has happened in the past year, we want to take a moment to give you an update on the current program goals, staffing and projects.

A JOINT INITIATIVE

As many of you know, Iowa law designates the Iowa Department of Public Health (IDPH) as the entity responsible for hearing screening and diagnostic assessment surveillance of all children under the age of 3 years. In years past, Iowa's Early Hearing Detection and Intervention (EHDI) system of care was a collaborative effort of two programs, Child Health Specialty Clinics and the Iowa Department of Public Health. The CHSC program was funded by the Health Resources and Services Administration (HRSA) and the IDPH program was funded by the Centers for Disease Control and Prevention (CDC).

The two programs then worked together to build a comprehensive and coordinated statewide EHDI system. IDPH ensured that all birthing facilities were providing universal hearing screens prior to hospital discharge, short-term follow up (missed and outpatient re-screens), data analysis and program evaluation while CHSC focused on assuring that all infants and toddlers who are deaf or hard of hearing receive timely and appropriate follow-up services including diagnosis, medical management and referral to early intervention (long-term follow up) and family support. Additionally, CHSC was responsible for the dissemination of risk factor letters and following babies at increased risk of developing late-onset hearing loss.

In January 2014, the IDPH EHDI program assumed responsibility for Iowa's long term follow up efforts and ensuring infants diagnosed with a hearing loss were referred to early intervention and family support. IDPH EHDI also resumed dissemination of risk factor letters to parents and the infants primary care provider. IDPH EHDI would like to personally thank Leslie Huber and Susan Rolinger for their assistance with the transition of these duties.

THE TEAM

You might ask yourself how did the transition change staffing and roles and responsibilities within the program. The EHDI staff already employed by IDPH did not change, however one new person was hired to work 30 hours as a follow up/family support coordinator when IDPH EHDI took on the HRSA EHDI grant. Following is a summary of roles and responsibilities of the staff within the IDPH EHDI program.

Tammy O'Hollearn has served as the state EHDI coordinator for Iowa since February 2006. She is program investigator/director for both the HRSA and CDC EHDI grants. She oversees project operations including key personnel, grant activities, coordination with partner agencies, education and outreach to providers and families, data design, collection, program analysis and evaluation of Iowa's EHDI system of care.

Jinifer Cox, EHDI program assistant has also been full time with the EHDI program since 2006. She inputs screening and diagnostic forms for Early Head Start and Parents As Teachers programs as well as out of state audiology providers that do not have access to the database. Jini conducts data quality assurance checks in the EHDI database to ensure complete and accurate data. She completes a weekly data match between the EHDI database and vital records data to ensure all occurrent births are entered and recorded in the EHDI database in a timely manner. She completes follow up on babies transferred out of state, makes referrals for babies born in Iowa in need of follow up care in their home state, serves as a technical assistant for data entry questions, and is token manager for the EHDI program.

"For me the satisfaction has come from two things, from seeing length of time from screening to diagnosis change significantly from 2006 when I started to today meaning children are being identified so much earlier and watching our system go from paper reporting where it was almost impossible to provide follow up to a web based system where results are shared instantaneously and follow up can begin early!"

- Tammy O'Hollearn

I love my job. I love the dedication of the EHDI team to the EHDI program.

- Jinifer Cox

UPDATES

By: Tammy O'Hollearn

Esha Steffen continues to serve as a full time follow-up coordinator. Her primary responsibilities include follow-up with families and primary care providers (PCPs) of children that did not pass or missed their hearing screens at birth, children in need of an audiological evaluation and referral to EA and family support. Esha works with the infant/child's audiologist or PCP to ensure a referrals were made upon diagnosis. This task amounts to approximately 250-300 calls per month. Additional responsibilities include quality assurance activities, training, data analysis and program evaluation. Esha is also bilingual, she speaks Hindi. She has been with the IDPH EHDI program since 2010 and has been instrumental in reducing Iowa EHDI's LTF/LTD rate by approximately 20 percent during her tenure.

"Every successful program has unique strengths that make it stand out. I love working with EHDI as I believe we have the most dedicated team that is not only passionate about their work but is committed to making a difference in the lives of children and families of Iowa. Team members value each other's opinions, input, and bring out the best in one another which plays an important role in making this program a huge success."

- Esha Steffen, MPH

Shalome Lynch began employment with the EHDI program in November 2014. Shalome is bilingual, her first language being Spanish. Her expertise and experience will enhance the EHDI program's ability to reach the Hispanic community. Shalome worked previously with the EHDI program through her work at Early ACCESS Iowa through Visiting Nurse Service. Much of her experience is working with individuals and families connecting them to appropriate resources.

To round out the team and ensure expertise in all areas of EHDI, the IDPH EHDI program took over a contract with the Center for Disabilities and Development for audiology technical assistance. Lenore Holte, clinical professor at the University of Iowa, has been with the EHDI program since its inception. Lenore is an expert in audiological screening, diagnosis and audiological services and supports. She teaches and also conducts research. Emily Andrews, pediatric audiologist with the Center for

Disabilities and Development provides technical assistance to birthing facilities and audiology clinics on the eastern half of the state while Bill Helms, retired Area Education Agency (AEA) audiologist serves the western half of the state. Emily has provided technical assistance to the hospitals and audiology clinics for over ten years. Bill is a recent hire. We pulled him out of retirement from Heartland AEA after Nick Salmon retired in October 2014.

We would like to welcome Drake Intern, Emily Sadecki. Emily joined the EHDI and Center for Congenital and Inherited Disorders programs on January 5, 2015. She has been assisting the EHDI program with redesigning the EHDI website and its content and creating Iowa EHDI News. In the coming months, she will assist the program in the development of a comprehensive report about the EHDI program, goals and data trends over the last few years. If there is time remaining before her internship ends, Emily will finalize the state hospital report cards and assist in the redesign of the EHDI Best Practices Manual.

ENDEAVORS

The EHDI team has been extremely busy over the last year. The program advanced data collection, evaluation, facilitated data sharing, increased quality assurance activities and used the results of various data analyses for decision-making related to programming and policy. The EHDI program continues to utilize quality improvement activities to influence change. Training was provided to birthing hospitals and Early Head Start/Parents as Teachers programs. The remaining private practice audiology clinics were trained on the use of eSP™ (EHDI database) and are using the data system to report hearing re-screens and diagnostic assessments. Tammy and Esha presented at the National EHDI conference in April 2014 on efforts to improve lost to follow up in Iowa. Dr. Sullivan, Dr. Holte and Tammy presented at the Iowa Academy of Family Physicians conference in November. IDPH EHDI partnered with Dr. Holte and a couple of audiology students to conduct research, specifically exploring the impact distance may have had on children needing a diagnostic assessment who ended up "lost to follow up."

Together, our team is constantly working towards improving processes and reaching more Iowa children.

REMINDER

The next Advisory Committee Meeting will be held on **April 2, 2015**. We value our committee members' input.

Contact Tammy O'Hollearn for special accommodations at least 48 hours in advance of the meeting.

View past meeting agendas, minutes and a list of committee members online at www.idph.state.ia.us/iaehdi.

how to order...

A Sound Beginning Brochure

To order additional hearing screening brochures in English or Spanish, please call the Healthy Families Line at **1-800-369-2229**.

Ask for publication IDPH 131 (English) or IDPH 131(S)(Spanish).

The brochure is available free of charge. Phones are answered 24/7.

Don't miss screening an infant

because of broken equipment.

If you are having problems with your hearing screening equipment, the Iowa EHDI program has a limited number of loaner screening OAE units available for hospitals to use while their screening equipment is being repaired. There is no charge for borrowing the equipment.

For information about loaner units, please contact:

Hearing Equipment Coordinator
(800) 272-7713

Lenore Holte
(319) 356-1168

Emily Andrews
(319) 384-6894

Bill Helms
(515) 450-1132

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
(515) 242-5639 - direct
(800) 383-3826 - toll free
tammy.ohollearn@idph.iowa.gov

EHDI Follow-Up Coordinator

Esha Steffen
Iowa Department of Public Health
(319) 491-4061 - direct
(800) 383-3826 - toll free
esha.steffen@idph.iowa.gov

EHDI Follow-Up/Family Support Coordinator

Shalome Lynch
Iowa Department of Public Health
(515) 725-2160 - direct
(800) 383-3826 - toll free

EHDI Program Assistant

Jinifer Cox
Iowa Department of Public Health
(515) 281-7085 - direct
(800) 383-3826 - toll free

Audiology Technical Assistance

Lenore Holte, Ph.D.
University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(319) 356-1168
lenore-holte@uiowa.edu

Emily Andrews, Au.D, CCC-A
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(319) 384-6894
emily-andrews@uiowa.edu

Bill Helms, Au.D., CCC-A
University of Iowa Hospitals and Clinics
Center for Disabilities and Development
(515) 450-1132
bhelms@isunet.net

Stories Spur **CHANGE**

By: Amy Pettit, Parent

A story of a mother's love, the power of collective voices and unwaivering persistence. Amy gives an account of her mission to ensure hearing aids for her son and all children in Iowa with hearing loss.

Recently I read an excellent book called *Storycatcher: Making Sense of Our Lives through the Power and Practice of Story*, by Christina Baldwin. The book maintains that we must share stories “that inform, inspire or activate us toward the betterment of our communities.” Baldwin’s book reminded me of the stories that were responsible for the onset of hearing aid funding in Iowa.

In 2006, at the age of four, my son was diagnosed with hearing loss. He would require hearing aids for the rest of his life as his loss was permanent.

Because my husband and I felt so alone, I reached out to two other families from my hometown who also had children with hearing loss. I felt much comfort in sharing our story with others who understood our grief. In the conversations and e-mails that we shared, we discussed how unfair it seemed that insurance companies in Iowa did not help with any of the hearing aid costs. After all, these were medical necessities that cost nearly \$4,000.

Our little group began to expand as we heard of other families who had children with hearing aids. I clearly remember one story from a mom in Muscatine. Both of her children were hard-of-hearing. Unfortunately, she did not have enough money to purchase two pairs of hearing aids. She had to make the gut-wrenching realization that she would only be able to provide a pair for the daughter with the least amount of hearing. Her other child would have to go without.

After several months of dialogue, we had about 40 families in this group. We organized a letter-writing campaign to Iowa legislators. We shared our stories in hopes that people in power would create change. In the notes that were written in 2006, we included our heartache over having children who could not communicate effectively without their hearing aids. We shared facts about states where insurance companies covered the cost of hearing aids. Additionally, we warned that without access to hearing aids, our children would suffer academically, socially, and emotionally.

As Christina Baldwin says, “Story has the power to open the heart...story is empathy in action between people” (46). After reading the letters, several families were invited to the Capital to explain why financial assistance

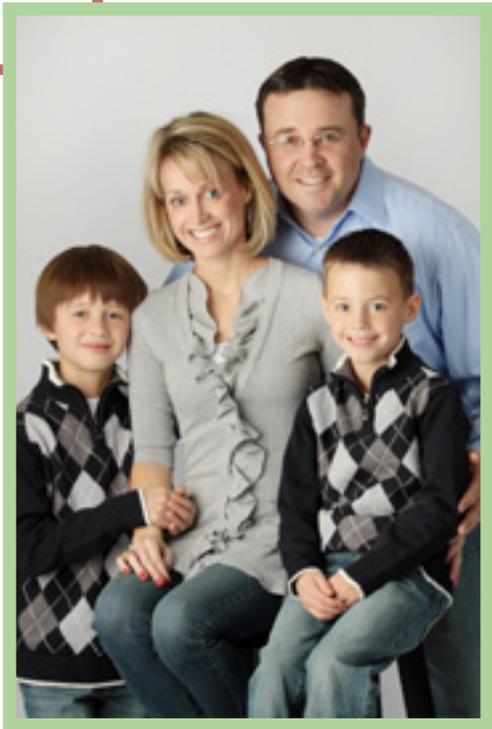
with hearing aids was so important to our families.

At the end of the 2006-2007 session, the bill mandating insurance companies to help pay for hearing aids did not pass. However, the State allotted over \$200,000 for hearing aids and audiological services. Our stories had been heard.

Every year since 2006, our legislators have set aside funds to help families pay for their children’s hearing aids. Hundreds of families have been helped through this money. Although insurance companies in Iowa are still not required to help pay for children’s hearing aids, we – the families who have children with hearing aids – are thankful that our stories have been validated. However, as budget cuts continue to occur, the need for our stories to be told and listened to is greater than ever.

In her book, Christina Baldwin says, “When we come upon a story like this one, or participate in a moment that has such rich potential to teach us how to be better human beings, we want to pass it along. We want the story to live...” (67). We will continue to tell our stories to political leaders, insurance companies and whoever will listen. And we won’t stop telling our story until all children in Iowa who need hearing aids can have access to them.

“And we won’t stop telling our story until all children in Iowa who need hearing aids can have access to them.”



FUNDING ANNOUNCEMENT

& a summary of 2014

2014 was another successful year for serving Iowa children and their families. Identifying hearing loss is just the first step. They must also be connected to the resources they need and many times insurance does not cover the cost of these services, such as hearing aids. Though there is no law in Iowa which requires hearing aid coverage for children, since 2007, the Iowa legislature has appropriated between \$160,000 to \$220,000 to the Iowa Department of Public Health to pay for hearing aids and/or audiological services for children who are not covered by health insurance. The next two pages showcase the impact that those funds were able to have on children in Iowa.

The current state of hearing aids in the union.

Requirements for health benefits plans vary state by state for ages covered, amount of coverage, benefit period and provider qualifications.

20 states have passed legislation to require insurance coverage for hearing aids for children.

7 states have legislation in process.

5 to 39 cents
range in cost per member per health plan

\$1,000 to Unlimited
range in amount covered by plans

\$135,237.46

Paid by Iowa taxpayers in the fiscal year ending in June 2014 to provide hearing aids, accessories and audiological services (e.g. diagnostic testing).

120 Iowa children benefited from these services.

Averages from 2014 claim payments

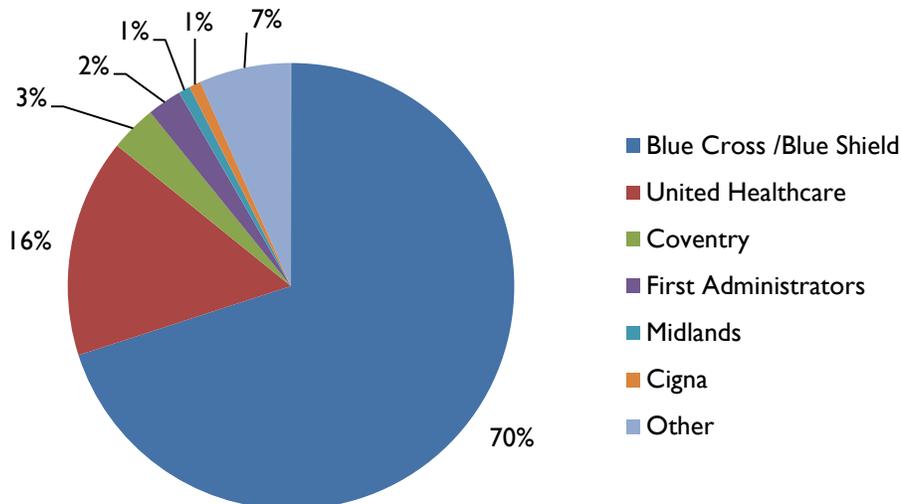
Number of claims processed	139
Gross dollars paid	\$135,237.46*
Refunds from 2013 payments	(\$12.09)
Refunds from prior years	(\$2,104.31)
Total number of children served during FY14	120
Average number of claims for served children	1.16
Average dollars paid per child	\$1,126.98
Average dollars paid per claim	\$972.93
Children with insurance payments	6

2014 claim payments by age

Age	Children Served	Percent	Dollars paid
0-2	23	19%	\$23,092.53
3-5	16	13%	\$21,664.98
6-10	46	38%	\$47,187.45
11-15	22	18%	\$27,114.36
16-20	13	11%	\$16,178.14

Insurance as Reported on 2014 Application Forms

The following chart illustrates the insurance status of children served under the Hearing Aids and Audiological Services Program.



Follow up Analysis

2012-2014

By: Esha Steffen, MPH

The primary purpose of follow-up, tracking and reporting is to ensure that all infants receive a hearing screening and timely follow-up services, if needed. The Iowa EHDl program works to progress toward the national EHDl goals (1-3-6) to ensure that: 1) all infants are screened for hearing loss no later than 1 month of age, 2) all infants who do not pass their hearing screening will have a diagnostic evaluation no later than 3 months of age, and 3) all infants diagnosed with a hearing loss are enrolled in early intervention services no later than 6 months of age. The follow-up usually begins 1-3 weeks following birth. Some of the follow-up activities performed by IDPH EHDl include contacting birthing facilities for any missing infants or incorrect data entry in the EHDl database (eSP™); collecting & entering results from audiology providers that serve very small numbers of children still using paper forms; and ensuring infants that are born out of hospital (home births, etc.) or transferred to an out-of-state facility receive a hearing screen in a timely manner. The follow-up coordinator also follows up with families and primary care providers (PCPs) of children who either miss or do not pass the initial hearing screen prior to hospital discharge. These contacts are made in an effort to encourage the families to bring infants back in for a follow-up hearing screen/assessment. Approximately, 250-300 phone calls are made each month by the IDPH EHDl team.

Table 1 shows the breakdown of referrals received by the IDPH EHDl in 2012-2014: Family Follow-up, NICU, Transfer, Out of State, and Home Births. These categories represent the total number of infants that needed follow-up in the last three years due to a missed screen or infants that do not pass their birth screen and do not return for a hearing re-screen. In summary, the IDPH EHDl program followed up on over 12,000 infants in 2012-2014.

Helpful definitions

Family Follow up

infants that either missed or did not pass their hearing screen at birth and need to be screened.

NICU/Watch

infants, in the Neonatal Intensive Care Unit (NICU) greater than five days, are tracked manually to ensure screening process in complete prior to discharge. These infants are included on the watch list along with infants that have been screened but their results haven't been entered into eSP™.

Out of State

infants born in Iowa but live out of state that did not pass their birth screen.

Transfer

infants born in Iowa and transferred to an out-of-state hospital for care.

Home Births

infants born in Iowa at home that are in need of a birth screen.

Total Number of Referrals by Category: 2012-2014

	2012		2013		2014 (Preliminary)	
	Number	Percent	Number	Percent	Number	Percent
Family Follow-up	1225	26%	1400	28%	1654	32%
NICU	2969	62%	3157	64%	2938	57%
Transfer	242	5%	186	4%	336	7%
Out of State	312	6%	209	4%	222	4%
Home Births	54	1%	0*	-	0*	-
TOTAL	4802		4952		5150	

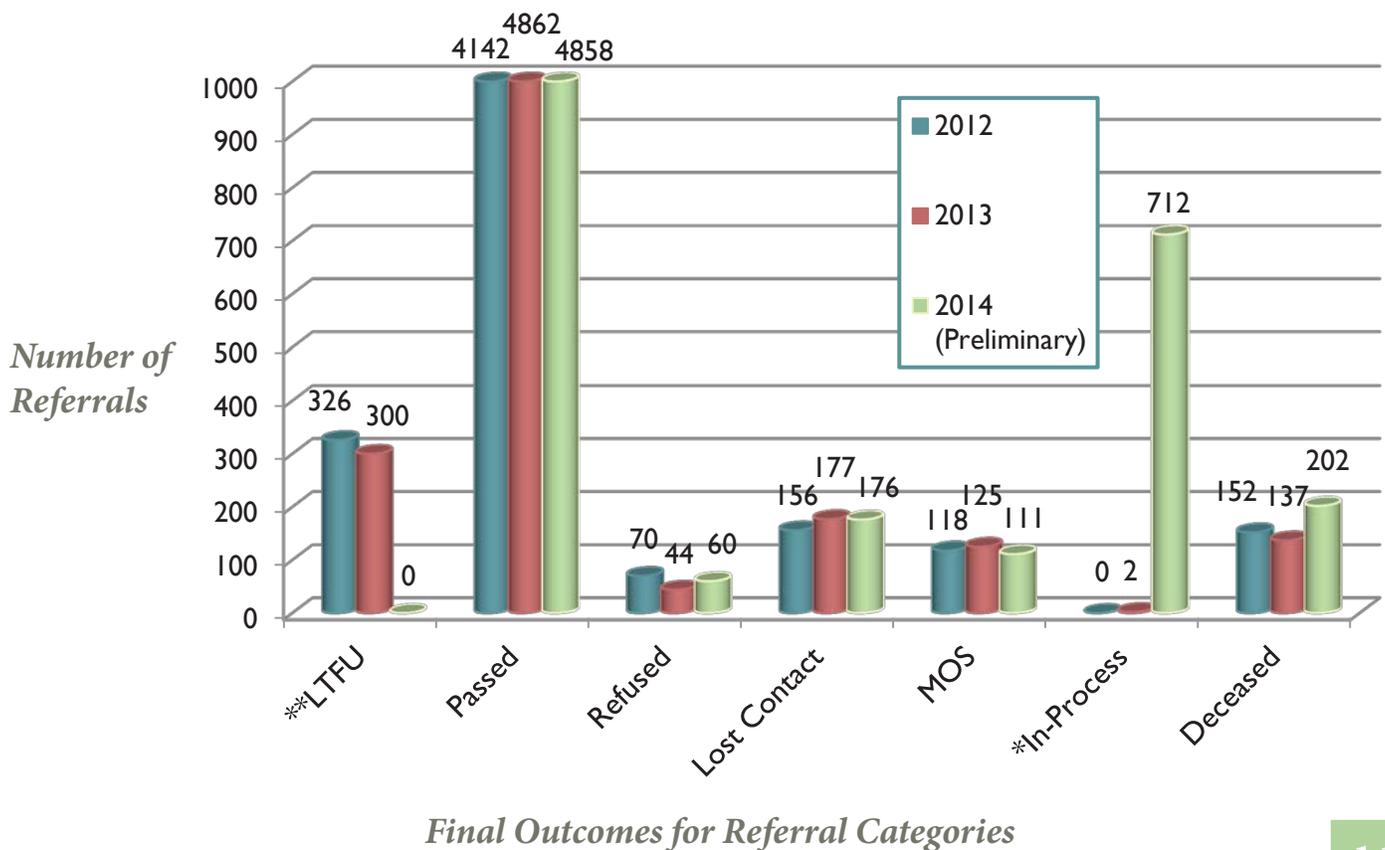
*Home births category was added to the Family Follow-up category starting in 2013

Graph I below shows the number of short-term follow up (STFU) referrals categorized based on their outcome for years 2012-2014. Each category is marked in the EHDI database based on their outcome after the follow-up is complete. It includes the following hearing outcomes:

- **Passed** includes infants who passed the hearing screen bilaterally.
- **Lost contact** includes infants who are considered “lost to follow-up” when they do not receive a follow-up hearing screen/diagnostic evaluation after several unsuccessful follow-up attempts including phone calls and letters to infants’ families and PCPs.
- **Deceased** includes infants who died of complications after birth.
- **Parental refusals** includes infants whose parents have declined the hearing screen.
- **Moved out of state (MOS)** includes infants who are born in Iowa but moved out of Iowa to another state.
- **In-process** includes infants that are in the NICU for an extended period of time and are being followed until discharged are discharged from the hospital and also, infants who are that are currently scheduled to receive a follow-up hearing screen/assessment and referral to early intervention services.*
- **Long-term Follow-up (LTFU)** This category was modified in the beginning of 2014 when IDPH took over administration of the HRSA Grant which was previously administered by CHSC (Child Health Specialty Clinics). From 2014 onwards, IDPH EHDI has been following up on all infants in need of an audiological assessment and early intervention services following the outpatient screen. Therefore, all infants under the LTFU category were moved to family follow-up. These changes resulted in higher number of referrals received by IDPH, increasing from 4802 in 2012 to 5150 in 2014 as shown in Table I.

It is also important to note that although majority of the categories shown in the graph below remained consistent from year to year, 80% of the referrals received by IDPH passed their initial/follow-up hearing screen.

Iowa EHDI STFU Follow up Referrals: 2012-2014



Follow up Analysis

2012-2014

(Continued)

In addition to the follow-up activities listed above, Iowa EHDI continues to engage in routine quality assurance activities to ensure accuracy of data within the EHDI database. Quality assurance activities help reduce the number of infants that would otherwise be lost to follow-up/documentation, ensures there are no duplicates and decreases data entry errors. This number has greatly reduced the number of infants lost to follow-up compared to the years past and continues to decline as we move forward.

In conclusion, the follow-up efforts at the IDPH EHDI show better outcomes that have, in turn, resulted in decreased miss or refer rates, decreased data entry errors, and more consistent reporting by audiology providers statewide. EHDI staff has been working diligently on a daily basis to ensure recommended services are received, reported and specific milestones and benchmarks are met. However, the current statistics can be further improved with a coordinated effort by birthing facilities, audiology providers, midwives and infants' medical home so all infants have access to timely evaluation and prompt initiation of early intervention services in the first six months of life, when needed.

A coordinated approach will also help minimize follow-up phone calls/letters that can create unnecessary stress for families. It is important that birthing facilities continue the following: decrease refer rates which in turn decreases the number of children in need of follow-up, emphasize to parents the importance of getting a hearing re-screen while they have parents' attention prior to hospital discharge and keep PCP's informed of the hearing screen results so an appropriate and timely referral for diagnosis can be made. Audiology providers are encouraged to report diagnostic results in a timely manner and appropriate referrals for early intervention are necessary to enhance the chances of infants receiving appropriate services once diagnosed. Similarly, midwives also play an important role for families of children born at home by increasing parental education about hearing screening including informing parents of the importance of hearing screening, what screening entails, and assisting parents with scheduling a hearing screen within the infants first month of life. Together, these efforts can significantly reduce the number of infants lost to follow-up/documentation and improve the hearing outcomes of children and families of Iowa.



Congrats!

Since the newsletter has not been active since a recent recognition of Lenore Holte, we want to take a moment to highlight her achievement.

An article by Lenore Holte, PhD, CCC-A, "Factors Influencing Follow-Up to Newborn Hearing Screening for Infants Who Are Hard of Hearing," has been selected for the 2012 Editors' Award for the American Journal of Audiology. The article selected for this award is the one that the Editor and Associate Editor feel meets the highest quality standards in research design, presentation, and impact for a given year. It is truly a high honor. The award was presented at the 2012 ASHA Convention on November 15.

Holte is a faculty member at the Wendell Johnson Speech and Hearing Center and oversees the audiology services for children at the Center for Disabilities and Development.



Lenore Holte

Another EHDI team member was also recognized for his many contributions on October 24, 2014 at the annual meeting of the Iowa Speech-Language-Hearing Association in Iowa City. Nick Salmon, recently retired EHDI audiologist, received the prestigious NielVerHoef award from the association. The purpose of this award is to publicly recognize individuals who have made extraordinary contributions to the professions of Speech-Language Pathology and/or Audiology and the Iowa Speech-Language-Hearing Association. Nick had a long career as supervisor for AEA hearing services, starting the audiology program in his AEA from scratch in 1975. He built an outstanding program in central Iowa and helped teachers and families understand the importance of school-based audiology services for children. After retiring from his AEA position, Nick joined the Iowa EHDI program as an audiological technical assistant, traveling the western half of the state, training screeners and spreading the word about the importance of newborn hearing screening and timely follow-up. Using his contacts in the state, his professional expertise and his considerable interpersonal skills, Nick built positive relationships with hospitals, schools, private practices and families that continue to benefit the Iowa EHDI program. Nick was also a founding board member of Iowa Hands and Voices and the organization is stronger today because of his involvement. In addition, Nick served as treasurer of the Iowa Speech and Hearing Foundation for several years. Nick has a genuine quality, which puts people at ease, and somehow makes everyone around him want to do the right thing. He is a skilled, intelligent and modest man, but most importantly, he is compassionate and kind. Over the last 40 years, he has combined these attributes to improve the lives of children and to benefit his profession of audiology in Iowa. Please join us in congratulating Nick on this well-deserved recognition!



Nick Salmon

WELCOME

There are a few new faces in our office. Say hello to Shalome Lynch and Emily Sadecki.

SHALOME LYNCH

Shalome Lynch started working with the EHDl team in November as the EHDl Follow up & Family Support Coordinator.



Shalome.lynch@idph.iowa.gov
(515) 725-2160

“Act as if what you do makes a difference. It does.”

a note from emily...

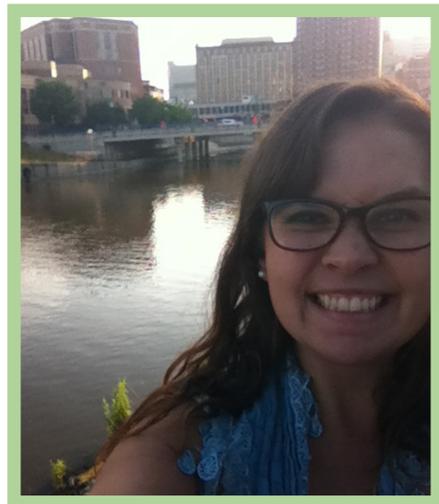
I am so excited to be working with EHDl. I am a public health fanatic and have fallen in love with its intersection between scientific investigation and the human narrative. A Minnesota native, I love spending time with my quirky family going up north, supporting my three younger siblings and discussing strange topics. When I am not immersed in school or work, I enjoy snuggling up with a good book, listening to NPR and exploring Des Moines. Serving the community is also important to me, particularly pertaining to women’s health and education initiatives. I hope to eventually become a physician and oscillate between clinical practice and public health policy advocacy. I am looking forward to my time here at the Iowa Department of Public Health and working with the passionate and dedicated staff that makes up the EHDl team.

a note from shalome...

I am happy to join the EHDl team at the Iowa Department of Public Health. As a result of my work serving families and children, I understand the importance of early intervention and follow up. I have worked in various settings with children and families including as a Parent Educator in Story County, a Case Manager and Care Coordinator in Polk and surrounding counties, and as a part of Coordinated Intake for Early ACCESS and MIECHV. I am an Iowa State University graduate and my first language is Spanish. I am recently married and have three children (that keep me VERY busy) ages 9, 5, and 18 months. We also have a dog name Shiloh. Through my work, I hope to continue supporting families in Iowa and strengthen partnerships with community partners. Please don’t hesitate to contact me with any questions!

EMILY SADECKI

Emily Sadecki joined us in January as an intern. She is currently a junior at Drake University pursuing a dual degree in biochemistry, cell and molecular biology and public relations.



emily.sadecki@idph.iowa.gov
(515) 725-2227



Equipment calibration

Did you know your equipment needs to be calibrated regularly? Not only does the equipment need to be inspected by your Biomedical department, it also needs to be checked to see if it is still operating within specific specifications so that it accurately measures what it is designed to measure. Depending on your particular equipment, calibration can be done on-site by a certified hearing equipment technician who comes to your facility, or the equipment is shipped to the manufacturer to be calibrated.

Not sure whether your equipment has been calibrated recently? Check for a sticker with “Date Calibrated” and/or “Date Calibration Due.” Most equipment needs to be calibrated annually unless the manufacturer specifies otherwise.

Contact

MSR Northwest (800-950-3277) for most OAE equipment and Biologic AABR.
Natus Medical (800-303-0306) for Algo AABR and Echoscreen OAE.

Unsure who to contact?

Email Wendy Harrison to help connect you to the appropriate people.

Beating the **BACKGROUND**

By: Mary Clausen, Retired Consultant, DHH, Mississippi Bend AEA 9

Each family's journey navigating hearing loss is different. Madison and her family describe the process of understanding how to incorporate hearing loss into their every day life. Together, they grow and learn, continually impressed by Madison's resilience and hard work.

As we sat in Applebee's for this interview, there was background music, distracting conversation in the next booth, and general restaurant noise. Through it all, Madison (with her bilateral cochlear implants) was able to listen and identify specific letters on a wall poster in response to her mother and father's named requests. We marveled at the ease at which Madison responded and all of the work that had gone into Madison's successful language and auditory development.

Madison Van Winkle was born during the fall of 2009. Her parents, Kristin and Jim, were as excited as any first time parents. After receiving several newborn screenings, Madison was referred for an ABR at 3 months which was followed closely with hearing aids and ear molds. Kristin and Jim took the diagnosis of Madison's hearing loss in stride. With both of them working in a hospital, they felt that there were far worse things they could be dealing with than hearing loss. They had been given information from the hospital and contacted Early Access.

By five months of age, Madison and her parents began receiving services from Kim Lestina, one of Grant Wood AEA's itinerant teachers for the deaf and hard of hearing. The Van Winkles credit Kim with providing them with the bigger picture of how to cope with a hearing loss. Kim shared websites and ICN sign language information, served as a resource for sign language and connected them to other

opportunities that were available for them as parents, as well as for Madison. Madison also received speech services through the GWAEA once a month which later increased as need was warranted.

Madison had a second ABR that showed a profound hearing loss, and at that time, Jim and Kristin decided that cochlear implants were the best decision for Madison. Cochlear implants were viewed as an additional tool for their daughter's success. They began their research about the different cochlear implants that are provided at the University of Iowa. Madison was scheduled for simultaneous CI surgery with Dr. Marlan Hanson in October of 2010. The Van Winkles reported that their only concern with surgery was the proximity of the facial nerve during implantation. They were comforted by the fact that the nerve is monitored closely during the surgery.

The Van Winkles met with several families in the area whose children had hearing loss and cochlear implants. This is one of the main recommendations that Jim and Kristin have for families in similar situations. They stressed that this was very educational for them. They saw a range of kids with CIs. One child was auditory and verbal, and another, although able to use auditory skills in communication, was also sign dependent. The Van Winkles adopted the mentality that cochlear implants would likely give Madison access to sound, but realized that she might need other communication methods as well.

NOISE

After contacting Cochlear Americas and Advanced Bionics, Madison's family chose the Advanced Bionics - Harmony CI processors. They chose Advanced Bionics based on the CI circuitry and the company support that was provided. When Madison was activated she laughed and smiled. She quickly adapted to her CIs and would become mad if they were taken off. Madison has continued to show excellent progress. Her progress can be seen on YouTube on the Van Winkles' account. Madison's parents became part of the BEA (Bionic Ear Association) Mentor program for Advanced Bionics.

Madison attended the Listen and Speak Up summer program at the University of Iowa Wendell Johnson Speech and Hearing Center for two summers. At three years of age, Madison began attending an integrated preschool 4 ½ days per week in October and also attends the local YMCA daycare. She uses a personal FM (I-connect) at preschool. The family has also pursued individual therapy for Madison at the Children's Center for Therapy in Iowa City.

Kristin and Jim wants parents to know that having a child diagnosed with a severe-profound hearing loss "is not a like attending a funeral or the end of the world. If you show them they are normal and treat them that way, communication will happen." They credit Kim for prepping them for what they might encounter along their journey. Kim discussed the

importance of talking to Madison, building strategies for themselves and for her in accessing information which includes cues in the environment: a speaker's lips, facial expressions, and body language. Jim and Kristin have learned that they should "never stop talking- never shut up". They believe it is important for parents of children with hearing loss to "always talk and describe what you see in order to give the child the language and words they need to hear."

"always talk and describe what you see in order to give the child the language and words they need to hear."

Madison has become a good self-advocate. She sits where she can see and hear what is happening in her environment – without prompting. Madison continues to see Kim twice a week for itinerant hearing support services and also receives weekly speech services within the school site to develop her communication, language, and articulation. Her parents report they have no regrets, but feel that "parents need to weigh their options and do what's best for you. There are lots of choices today."

Thanks to Jim, Kristin, and Madison Van Winkle and Kim Lestina for their willingness to be interviewed for this article.



Risk Factors

for early childhood hearing loss

One of the challenges faced by all EHDI programs involves monitoring babies who pass the newborn hearing screen, but are at high risk to develop hearing loss before they acquire speech and language. The Joint Committee on Infant Hearing has made recommendations about what risk factors to include in monitoring. It is also important to understand the relationship between these risk factors and congenital hearing loss. In the Iowa EHDI legislation, reporting of high risk factors for early childhood hearing loss became mandatory at the beginning of 2007. Last year Amy Carlson, a graduate student in audiology, and Lenore Holte, both from the University of Iowa, agreed to help IDPH by investigating the relationship between these risk factors and the presence of hearing loss in Iowa children under the age of three years.

Data was collected in December 2012 from the online Iowa EHDI database (eSP™) for the purpose of answering the question of which risk factors associated with congenital and delayed onset (before three years of age) hearing loss are most frequently related to diagnosed hearing loss in Iowa from birth years 2007-2010. Risk factors included in the study are listed to the right and were recommended by the Joint Committee on Infant Hearing (2007). They are listed in eSP™.

- Craniofacial anomalies
- Family history of childhood hearing loss
- Meningitis
- Birth weight <1500g
- Congenital CMV
- Congenital Herpes
- Congenital Rubella
- Congenital Syphilis
- Congenital Toxoplasmosis
- Neurodegenerative disorder
- Other congenital condition
- Syndrome
- Transfusion
- NICU stay >5days
- APGAR score 0-4 at 1 minute
- APGAR score 0-6 at 5 minutes
- Assisted Ventilation
- Extra-corporeal membrane oxygenation (ECMO)
- Head injury
- Other postnatal infection
- Otitis Media >3 mo
- Ototoxic medication exposure
- Parental concern

Findings

Prevalence of early childhood hearing loss in Iowa

During birth years 2007 to 2010, 154,730 Iowa infants received a newborn hearing screen.

Congenital Hearing Loss	272	1.8 per thousand	★2.4 Iowa babies per thousand have permanent hearing loss by age 3.
with risk factors	127	47%	
without risk factors	145	53%	
Delayed Onset Hearing Loss	92	0.6 per thousand	
with risk factors	34	37%	
without risk factors	58	63%	

It is important to note that many of these babies who have no reported risk factors may actually have risk factors that were unreported or had asymptomatic and undetected congenital CMV or recessive inheritance for hearing loss. 85-95 percent of congenital CMV is asymptomatic.

Percent of children with risk factors in children with hearing loss by age 3

Risk Factor	% of CHL	% of DOHL
Craniofacial	0.6	2.6
Family History	0.2	1.2
Meningitis	3.3	0
Birth Weight <1500g	0.5	1.5
Congenital CMV	12.5	0
Neurodegenerative Disorder	7.4	0
Other Congenital Condition	0	0.5
Syndrome	2.1	4.3
Transfusion	0	1.4
NICU Stay >5 days	0.2	1.2
APGAR Score 0-4 at 1 Minute	0.1	0.9
APGAR Score 0-6 at 5 Minutes	0	1
Assisted Ventilation	1.3	2.6
Head Injury	3.8	0
Ototoxic Medication Exposure	0.2	1.1
Parental Concern	0	0.6

★ Though they are still risk factors, the following conditions were not detected during this sample period: congenital herpes, congenital rubella, congenital syphilis, congenital toxoplasmosis, extra-corporeal membrane oxygenation, other postnatal infection and otitis media >3 months.

★ Congenital CMV is vastly underreported, so this figure may not reflect the true impact.

★ The biggest limitation of this data analysis is that we are not sure how consistently risk factors are actually being reported in eSP™. For instance, research literature shows that extra-corporeal membrane oxygenation (ECMO), especially in babies with congenital diaphragmatic hernia (CDH), is highly associated with congenital and delayed onset hearing loss. This risk factor was hardly ever reported. This group is likely reported as having a NICU stay of more than 5 days, without specification about ECMO.

Thank you.



Iowa's Early Hearing Detection & Intervention Program

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