No More Lost to Documentation

What made these states successful?

Tammy O'Hollearn, EHDI Director for Iowa
Tanya Green, Program Chief, Maryland EHDI
Wendy Welsh, OZ Systems

IDPH
IOWA Department of PUBLIC HEALTH

Maryland
DEPARTMENT OF HEALTH

oz systems
Screening Solutions.
Improving New Lives.

Babies Don't Want to be Lost to Follow-up or Lost to Documentation

- There will always be lost to follow-up (e.g. parental choice)
- But there does not need to be lost to documentation
- How did Iowa and Maryland reduce lost to documentation?
- How do we get providers engaged in reporting results & outcomes?

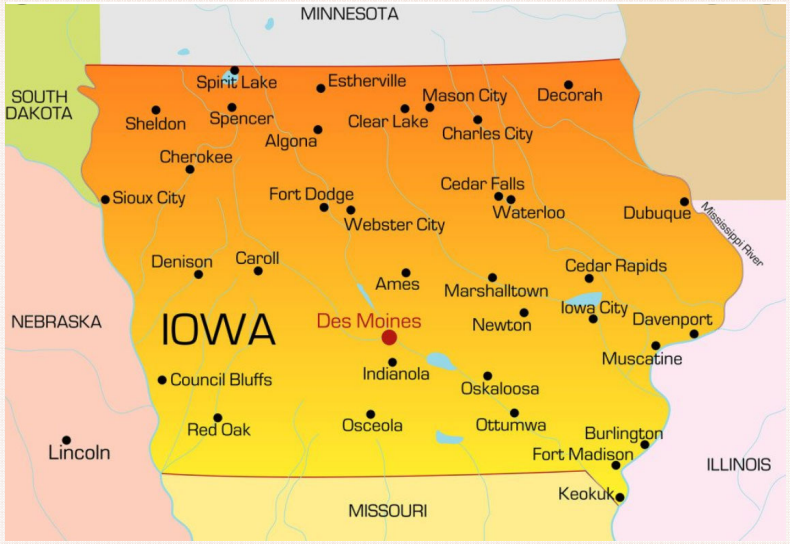
IDPH
IOWA Department of PUBLIC HEALTH

Maryland
DEPARTMENT OF HEALTH

oz systems
Screening Solutions.
Improving New Lives.

Geographic Comparison

	Iowa	Maryland
Population	3,156,145	6,006,401
Land Area	55,857.1 sq. mi	9,774 sq. mi
Population Density	54.5 people/sq. mi	625 people/sq. mi
Urban	64.3%	82.2%
Rural	35.7%	17.8%
Border States	6- MN, WI, IL, MO, SD, NE	5 - DC, VA, PA, WV, DE



State Comparison

	Iowa	Maryland
Year EHDI program began	1992 grass roots group	July 1 2000
Legislation	Yes	Yes
Rules & Regulations	Yes	Yes
State Funding	No state funding covering the EHDI program	Covers a portion of EHDI Program salaries
Insurance	Insurance pays for hearing screen as part of the Global Newborn Care DRG. OP and DX depends on insurance, but often pays. Medicaid pays.	Insurance companies are required to cover newborn hearing screens that originate in Maryland
EHDI data management system implemented	1999	2008

State Comparison

	Iowa	Maryland
# of births	39,000 – 40,000	68,000-70,000
# of hospitals	62 with too more planned to close in summer. In 2006 IA had 81.	33
# babies needing follow-up	2200-2500 infants per year in need of an screen • All infants, regardless of nursery, get an outpatient screen • Would like NICU babies to go straight to diagnostic (Dx) Approximately 500 need diagnostic assessment	Approximately 3,000 infants per year need an outpatient screen Approximately 1,000 infants per year need diagnostic assessment
# of Audiologists serving them	77 total performing hearing screens, sedated or unsedated Dx assessments. 10 perform sedated Dx assessments. 40 Area Education Agency educational audiologists perform screens and some unsedated ABRs	Approximately 160 Approximately 5 in-state facilities perform sedated ABRs, and Children's National Medical Center and Georgetown University Hospital in Washington, DC and INOVA in Virginia
% of audiologists reporting	99%. If IA learns of a new provider through follow-up, IA EHDI contacts them and get them trained on reporting in the EHDI system.	100%
Border States	Laws do not apply to them, but good cooperation. IA EHDI works directly with the facility or the EHDI coordinator in that state. Iowa law allows IA to share with bordering states for follow-up purposes. Clinics in bordering states help serve Iowa babies with diagnostic assessments.	Laws do not apply to them but have good cooperation. Reciprocal access to D.C. EHDI system since they both use OZ Systems

MARYLAND NEWBORN SCREENING PROGRAM

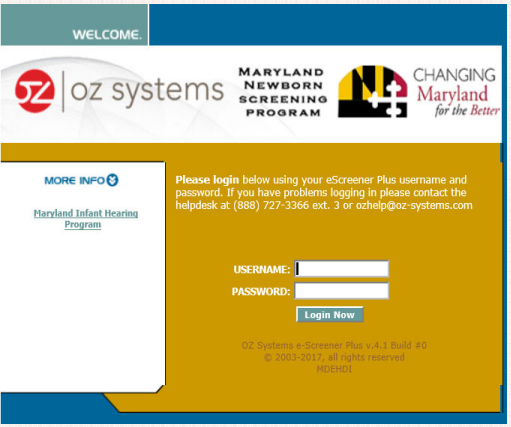
CHANGING Maryland *for the Better*

Maryland EHDI Program

https://phpa.health.maryland.gov/genetics/Pages/Infant_Hearing_Program.aspx

Legislation and Rules

- July 1, 2000 Universal Newborn Hearing Screening legislation passed; revised July, 2014
- June, 2015 - Rules and Regulations strengthened the Law
  - .08 Procedures for Audiologists and Licensed Professionals Conducting Audiological Screening or Evaluations. A. An audiologist or a licensed professional who performs a hearing screening or audiological diagnostic evaluation on a child younger than 5 years old due to the presence of a risk factor as listed in Regulation .04 of this chapter or in follow-up to the birth hearing screening of a newborn or infant who did not receive or did not pass the birth hearing screening shall: (1) Within 2 business days: (a) Report the results of the screening or audiological diagnostic evaluation to the Program in the Department database; (b) Document recommendations and referrals provided in the Department database; and (c) Confirm or update the demographic information of the child or infant in the Department database; and (2) Within 7 business days, notify the appropriate early intervention program at the Maryland State Department of Education of any child younger than 5 years old confirmed to have or strongly suspected of having a permanent hearing status of any type or degree as described in §B of this regulation which is sufficient to interfere with the acquisition and development of speech-language skills with or without the use of sound amplification. B. A child younger than 5 years old is strongly suspected of having a permanent hearing status if evidence or clinical judgment exists which indicates that there is a high probability of a permanent hearing status of any type or degree which is sufficient to interfere with the acquisition and development of speech-language skills.
  - Regulations require audiologists and licensed professionals conducting audiological screenings or evaluations to report results to the Maryland Department of Health
  - Specifies timeframe for reporting
  - Specifies the Department within the State to receive the report
  - Allows the Department to specify how the report is to be submitted
- Regulations require birth center staff and midwives to report birth event to the Department (via the MD EHDI database)



EHDI Information System

- Newborn Hearing Screening and Screening Follow-up information is needed by:
  - Maryland Department of Health/MD EHDI
  - Physicians
  - Audiologists
  - Part C Program
- Beneficial to have information in one location
- If a family moves out of state, chooses private services, receives follow up services after several years, or parents are unable to recall the newborn hearing screen history, data can be located in the MD EHDI database to assist with follow up efforts
- Audiologists who work within early intervention programs have provided positive feedback about the MD EHDI data system and how it helps them provide needed follow up because they can see newborn hearing screen history and follow up test results
- Audiologists assessing babies are challenged because it is one more place to document

Challenges

- MD EHDI has overcome many challenges but a few remain. The following changes would improve current processes but will increase staff time:
  - Train and encourage audiologists to contact MD EHDI prior to appointments to request database access to patient
  - Train and encourage audiologists to provide MD EHDI with the following information when requesting file access: mother's full name, baby's name, baby's date of birth, birth facility
  - For audiologists, having an additional database to document results and follow up information is a challenge
  - Lack of ABR facilities in some regions of the state
- Need for additional sedated ABR facilities in the state.

Maryland
DEPARTMENT OF HEALTH

Successes

- The Regulations are the Program's most valuable asset and have made a great impact on reducing loss to follow up and loss to documentation
- Prior a system was in place but no one was required to use it.
- Reporting rates have improved since the regulations became effective in 2015

The cooperation of MD EHDI stakeholders has lead to the Program's current success in reducing loss to follow up and documentation!

IDPH
IOWA Department of PUBLIC HEALTH

Iowa EHDI Program

https://idph.iowa.gov/ehdi

EHDI
Iowa's Early Hearing Detection & Intervention Program

Legislation and Rules

- 2003 – Law in effect but very vague
- January 1, 2004 - Rules and Regulations strengthened the Law - https://www.legis.iowa.gov/docs/iac/chapter/641.3.pdf
  - Any birthing hospital, birth center, physician, audiologist or other health care professional required to report information pursuant to Iowa Code section 135.131 shall report all of the following information to the department relating to each newborn's hearing screening within six working days of the birth of the newborn and within six working days of any hearing rescreen, utilizing the department's designated reporting system.
  - Any health care professional conducting newborn hearing screens, rescreens, or diagnostic audiological assessments shall report the results within six working days for any child under three years of age to the department utilizing the department's designated reporting system. The health care professional shall conduct the diagnostic hearing assessment in accordance with the Pediatric Audiologic Diagnostic Protocol prescribed by the department at www.idph.iowa.gov. Results of a hearing screen, rescreen or diagnostic audiological assessment shall be reported as follows: (see link above for all the details)
- Added to the Audiology Licensure under Grounds for Discipline , "Licensees shall comply with universal newborn and infant hearing screening requirements within Iowa Code section 135.131 and 641—Chapter 3."
- Rules MUST BE EXPLICIT – not vague (no room for interpretation)
  - Who MUST report
  - Timeframe they have to report – within 6 days
  - Who to report to
  - Where they report ("department's designated reporting system") – not fax, paper, verbal
  - What needs to be reported

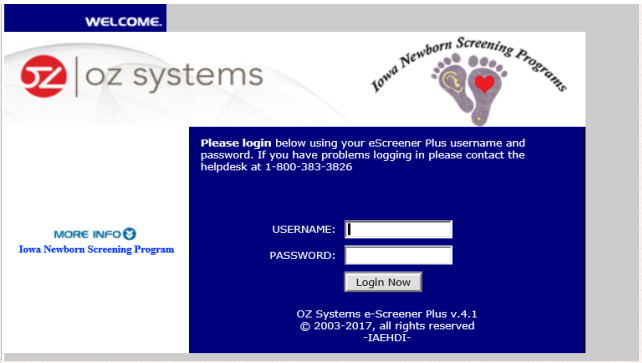
IDPH
IOWA Department of PUBLIC HEALTH

Audiological Follow-up

- Area Education Agencies
  - Educational audiologists performing unsedated ABRs
  - DOH helped AEA obtain equipment and provided training and coaching
  - Only 4 AEAs provide these services
  - EHDI would like all AEAs to provide unsedated ABRs in their area, but others declined for various reasons (e.g. cost, low incidence)
- Private practice ENT/Audiology Clinics
  - Only 8 able to provide unsedated ABRs – not spread around the state
- Only 3 diagnostic centers in Iowa able to perform sedated ABRs
  - Iowa Ear, Unity Point-Des Moines and University of Iowa Otolaryngology
- We have a number of children from Iowa diagnosed at Boys Town (Omaha, NE) a few from places like South Dakota & Minnesota. All of these we have good relationships.

Iowa Newborn Screening Information System

- Birthing facilities (hospitals) and audiologists performing a hearing screen, re-screen or diagnostic assessment on children under the age of 3 MUST report using Iowa's newborn screening information system (INSIS) and NOT use paper reporting forms.
- We confirm all infants born in Iowa are accounted for in INSIS through a data match (not electronic yet, but manual). We know the outcome of every child born in Iowa, as well as case management or care coordination on all attempts to reach the family and infant's primary care provider to get the child back in and moved onto the next step.
- We do use our data to inform policy development, quality improvement and also give it back to our providers so they can also monitor their progress or meeting best practices.



Iowa Newborn Screening Information System

- February 2006, only 5-6 birthing facilities reported into INSIS
- End of 2007, 81 birthing facilities and all educational audiologists reported into INSIS
- Over 80,000 paper forms needed to be entered into the INSIS system.
- Started training private practice audiologists to use INSIS.
- We went from not knowing who needed follow-up or who was identified with hearing loss to knowing who needed follow-up, which facilities needed more technical assistance, etc.
- Decreased our numbers
  - 2009 - 60.9% LTF/LTD
  - 2011 – 35% LTF/LTD – in 2010, IA EHDI brought all care coordination in-house
  - 2016 - 14.3% LTF
  - 2017 – 19.1% LTF - increase due to cut in funding leading to reduction in personnel doing follow-up
  - 2018 – 13.2% LTF How? Following up with families directly & primary care providers and providing education and outreach

Challenges

- Need sustainable funding - as federal funding was decreased or a portion redirected (HRSA redirecting 25% to family support).
- Iowa EHDI only has 2 full time staff to perform:
  - Care Coordination for infants that did not pass their hearing screen at birth through diagnosis to early intervention
  - Write grants and complete grant reports,
  - Write contracts and request for proposals
  - Facilitate the EHDI advisory committee meetings 3 x year and learning community
  - Perform outreach or education
  - Provide technical assistance,
  - Monitor surveillance and clean the data (de-duplication and correct other errors or follow-up on missing information)
  - Complete a yearly data match between EHDI and vital records to complete the CDC EHDI annual report
  - Perform program evaluation and data analysis.
  - Spend time on various committees EHDI related at the state and national level.

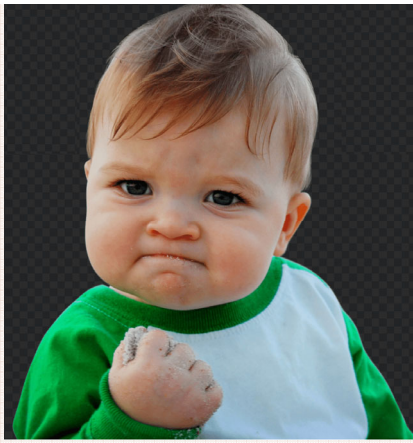
IDPH
IOWA Department of PUBLIC HEALTH

Challenges

- Why don't physicians give immediate attention to hearing loss like with vision or blood spot? There needs to be more public awareness for physicians and ENTs. Even some of the audiologists do not see the significance of early identification.
  - We need more national education especially for physicians
- Not all border states respond to requests for information either because they don't collect it, don't have time, etc.

IDPH
IOWA Department of PUBLIC HEALTH

Successes



- The Regulation – before it we had no way to know if babies were getting follow-up
- Statement from Attorney General office says providing access to audiologists is a continuation of their care. Anyone who uses INSIS agrees to terms of HIPPA. INSIS provides a subset of information and the audiologist can assign themselves as a provider for that child giving them access.
- We have 1 dedicated follow-up coordinator in Iowa Dept. of Public Health who obtains information by contacting parents directly and physicians to find the information. Text messaging has provided another way to contact parents. We also make calls around dinner time (not just business hours)
- 99% of our audiologists are reporting.
- Memorandum of Agreement in place with Early Intervention partners to share referral and enrollment data on each child versus aggregate.
- We know outcome to every child in our state – can tell you how many contacts we have with them. Data is clean. A lot of quality assurance to make data clean and accurate. Good individualized verifiable data.
- Children are lost to follow-up NOT lost to documentation.
- We appreciate all the cooperation we receive from everyone involved in EHDI

How providers report outcomes into the information system

- The birth facility or Dept. of Health can assign a provider in the system giving the provider access to the child's screening data and ability to report their outcomes. User roles are defined in the system and determine what the user can and cannot do.
  - There are flexible ways for audiologists to locate records and enter information, capturing key CDC data that the state receives in real time
  - Automated ECI referral to make it worth the Audiologists efforts – they can locate the correct provider and make referrals that go directly to ECI.
  - Customized to meet state needs

IDPH
IOWA Department of PUBLIC HEALTH

Maryland
DEPARTMENT OF HEALTH

oz systems
Screening Solutions.
Improving New Lives.

Support for Audiologists

AUDIOLOGY TODAY

How to Effectively Access and Collaborate with Early Hearing Detection and Intervention Systems

By Caitlin Sapp | Wendy Crumley Welsh

Appears in Audiology Today September/October 2019

The Early Hearing Detection and Intervention (EHDI) program and its information system (EHDI-IS) can play a pivotal role in improving patient outcomes, regardless of the type of intervention a family chooses.

Public health agencies, in conjunction with Early Hearing Detection and Intervention (EHDI) programs, monitor the results of newborn screening outcomes, newborns with risk factors for the late onset of hearing loss, the prevalence of confirmed hearing

https://www.audiology.org/audiology-today-septemberoctober-2019/how-effectively-access-and-collaborate-early-hearing-detection

AUDIOLOGY ONLINE

AUDIOLOGYONLINE Log In Join Now

How It Works | Continuing Education | Career Center | Journal | Partners | Our Experts | Group Learning

The Pediatric Audiologist in Early Hearing Detection and Intervention (EHDI)

Caitlin Sapp, AuD, CCC-A, Wendy Crumley Welsh, MS, CCC-A

June 3, 2019

Articles / Hearing Evaluation - Children / Pediatrics / The Pediatric Audiologist in Early Hearing Detection and Intervention (EHDI)

https://www.audiologyonline.com/articles/pediatric-audiologist-in-early-hearing-25248