Improving Loss to Follow-up Rates Among Iowa Babies: Strategies for Success

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Disclosures

We have no relevant financial or nonfinancial relationships in the products or services described, reviewed, evaluated or compared in this presentation.

Learning Objectives

- Participants will be able to identify several tests of change or strategies used to reduce lost to follow up/documentation percentages in Iowa
- Participants will be able to describe how data can be used to evaluate a quality improvement strategy
- Participants will be able to identify quality assurance activities Iowa EHDI uses in their daily activities to ensure complete and accurate data

Presentation Objectives

- Describe the current state of Iowa EHDI System of Care (SOC)
- Discuss EHDI milestones, program goals, and web-based data system
- Describe the importance of active follow-up & quality assurance checks
- Identify issues that contribute to lost to follow-up/documentation (LTF/LTD) rates
- Describe strategies used to address LTF/LTD rates
- Discuss successes, challenges, and future efforts of Iowa EHDI SOC

Background on Iowa EHDI Program

Iowa EHDI Mission Statement

Iowa's Early Hearing Detection and Intervention (EHDI) program works to ensure that all newborns and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, medical intervention and family support.

EHDI Program Goals

- Develop and sustain a comprehensive coordinated SOC for EHDI
- Provide technical assistance to birthing hospitals, audiologists, and healthcare providers related to hearing screening program , best practices and their responsibility under the law.
- Statewide implementation of a Web-based surveillance system
- Facilitate data integration linkages with to minimize infants "lost to follow-up".
- Meet the National EHDI Goal of **1-3-6**.
- Review data to identify children with potential for hearing loss to ensure those children receive appropriate, timely EI services and family to family support
- Collaborate with IDEA, Part C (Early ACCESS) to strengthen early intervention services for children who are deaf or hard-of-hearing.

EHDI Milestones

- EHDI law passed in 2004
- Statewide implementation of EHDI Web-based data system (07)
- Established GBYS program
- Parents/PCPs of infants with risk factors notified/informed of recommended follow up
- EHDI website developed for parents/professionals
- EHDI newsletters published quarterly
- Improved newborn screening/fup through education & training
- Improved follow-up rates for Spanish speaking families
- Developed outstanding relationships with neighboring states
- Decreased the number of children LTF/LTD
- Began evaluation and analysis of data, distributed quarterly reports

eSP™ - EHDI Database

- Web based data system which tracks outcome of every occurrent Iowa birth and children under 3 w/screen/assess.
- Approximately 400 users, only permission to applicable children
- Used by EHDI staff, hospitals and audiology providers
- Used to complete annual CDC survey and provide data for grants
- Used to track needed follow-up and referrals and data analysis
- Used as a tool to review hospital and audiology best practices or lack thereof
- Used for program evaluation

Quality Assurance

Quality Assurance

Quality assurance checks completed by Iowa EHDI program assistant, follow-up coordinator, and EHDI coordinator:

Weekly

- Data match with Vital Records (VR)
- Ensure babies are marked as deceased in eSP following receipt of VR report
- Hospital confirmations for children missed or in the NICU
- Create referral spreadsheets (babies who missed or referred)
- Refusals – ensure no normal or other results in the records

Quality Assurance Cont'd

Monthly

- Merge duplicate records
- Follow up on assessments showing "sessions in process"
- Mark kids with hearing loss as hearing loss complete
- Mark in-process kids to "lost contact" following short-term follow up processes
- Mark "Lost" kids back to "in process" if recently screened
- Request EA and family support information
- Review of kids that skip from birth screen straight to diagnostic assessment
- Review of data entry errors in eSP™ including infants' names, zip codes, phone numbers, screen dates and times, etc.

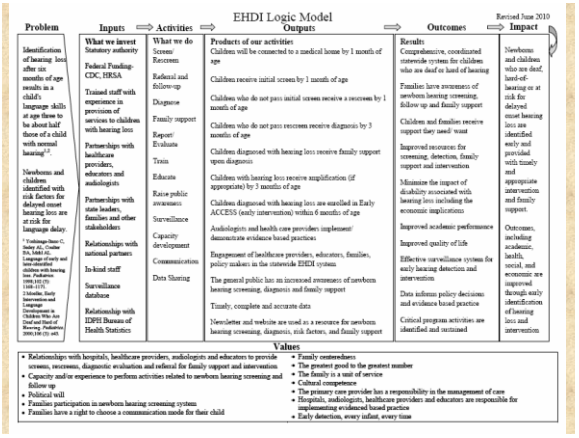
Birthing Facility Progress Reports

- Distributed to all birthing facilities on a quarterly basis
- Highlights strengths and areas for improvement for each facility including:
  - Summary of child outcomes (total births, total passed, referred, missed, etc.)
  - Summary of age of the infant when screened at birth and OP setting
  - Refer and miss rates in comparison to the state and national goal average, as well as facilities of the same level
  - Number of children missing in the EHDI database
  - Number of missing PCP's for infants in the EHDI database
  - Adherence to EHDI Protocol and Law (e.g. avg. # of days to entry (screen results) into eSP™, avg. # of screens)

Program Evaluation

Logic Model & Planning

- Form Steering Committee
- Assess current evaluation tools
  - Data analysis
  - Program Indicators
  - Logic model
- Identify evaluation questions of interest
- Prioritize evaluation focus areas
- Develop evaluation tools
  - Surveys
- Evaluate program components
- Provide results/feedback to stakeholders



EHDI Logic Model

Revised June 2010

Problem	Inputs	Activities	Outputs	Outcomes	Impact
Identification of hearing loss after six months of age results in a child's language skills at age three to be about half those of a child with normal hearing[1,2] Newborns and children identified with risk factors for delayed onset hearing loss are at risk for language delay. * Yoshinaga-Itano C, Sedey AL, Coulter DK, Mehl AL. Language of early and later-identified children with hearing loss. *Pediatrics* 1998;102(5):1161-1171. 2 Moeller, Early Intervention and Language Development in Children Who Are Deaf and Hard of Hearing, *Pediatrics* 2000;106(3):e43.	**What we invest** Statutory authority Federal Funding- CDC, HRSA Trained staff with experience in provision of services to children with hearing loss Partnerships with healthcare providers, educators and audiologists Partnerships with state leaders, families and other stakeholders Relationships with national partners In-kind staff Surveillance database Relationship with IDPH Bureau of Health Statistics	**What we do** Screen/ Rescreen Referral and follow-up Diagnose Family support Report/ Evaluate Train Educate Raise public awareness Surveillance Capacity development Communication Data Sharing	**Products of our activities** Children will be connected to a medical home by 1 month of age Children receive initial screen by 1 month of age Children who do not pass initial screen receive a rescreen by 1 month of age Children who do not pass rescreen receive diagnosis by 3 months of age Children diagnosed with hearing loss receive family support upon diagnosis Children with hearing loss receive amplification (if appropriate) by 3 months of age Children diagnosed with hearing loss are enrolled in Early ACCESS (early intervention) within 6 months of age Audiologists and health care providers implement/ demonstrate evidence based practices Engagement of healthcare providers, educators, families, policy makers in the statewide EHDI system The general public has an increased awareness of newborn hearing screening, diagnosis and family support Timely, complete and accurate data Newsletter and website are used as a resource for newborn hearing screening, diagnosis, risk factors, and family support	**Results** Comprehensive, coordinated statewide system for children who are deaf or hard of hearing Families have awareness of newborn hearing screening, follow up and family support Children and families receive support they need/ want Improved resources for screening, detection, family support and intervention Minimize the impact of disability associated with hearing loss including the economic implications Improved academic performance Improved quality of life Effective surveillance system for early hearing detection and intervention Data inform policy decisions and evidence based practice Critical program activities are identified and continued	Newborns and children who are deaf, hard-of-hearing or at risk for delayed onset hearing loss are identified early and provided with timely and appropriate intervention and family support. Outcomes, including academic, health, social, and economic are improved through early identification of hearing loss and intervention

Values

- Relationships with hospitals, healthcare providers, audiologists and educators to provide screens, rescreens, diagnostic evaluation and referral for family support and intervention
- Capacity and/or experience to perform activities related to newborn hearing screening and follow up
- Political will
- Families participation in newborn hearing screening system
- Families have a right to choose a communication mode for their child
- Family centeredness
- The greatest good to the greatest number
- The family is a unit of service
- Cultural competence
- The primary care provider has a responsibility in the management of care
- Hospitals, audiologists, healthcare providers and educators are responsible for implementing evidenced based practice
- Early detection, every infant, every time

Surveys

Parent

- Birthing facility & out of home births

Database

- Birthing facilities and audiologists use

Birthing facilities

- Screening and referral practices
- EHDI Tips
- Progress Reports

Physician

- Screening, recommended follow up and risk factor knowledge

Audiology

- Screening, referral for diagnostic, EI and GBYS

Survey Lessons Learned

- Parent
- Database
- Birthing facilities
- Physician
- Audiology

Follow-up

Follow-up Processes

- Data match with Vital Records report to ensure all babies are accounted for in the EHDI database
- Referral spreadsheet created bi-monthly includes: NICU; Home Births; Out of state; Transfer babies; Family Follow up
- Family Follow up: Contact families and PCPs of children who initially missed or referred on their birth screen; 250-300 calls/month
- Referrals to Early ACCESS Iowa for Spanish speaking families
- Follow up with hospitals, audiologists regarding missing or incorrect results

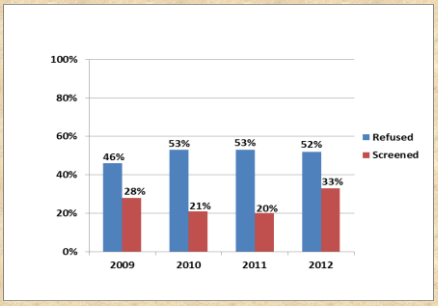
Follow-up Processes Cont'd

- Referrals to Area Education Agencies (AEAs)
- Contact birthing facilities/AEAs/audiology providers to request/confirm results
- Send letters to families with no follow-up screen scheduled
- Follow up on previous spreadsheets
- Move kids to "lost" after completion of protocol
- Data analysis to track response rates in an effort to meet the 1-3-6 month national goals

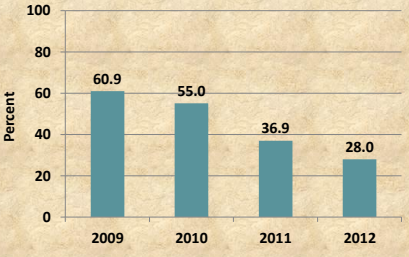
Home Birth Follow up

- Letter, EHDI Brochure and parent story included in the birth packets.
- Letter with same info and refusal form sent to home birth families after birth if no initial screen.
- Home births that refuse per Vital Records are moved to "Refused-Consent not given."
- Follow-up Coordinator contacts mom and the child's PCP if available in eSP™.
- Newsletter article and non state/federal educational materials developed and mailed midwives to increase awareness and encourage them to assist families in locating a screening provider

Home Births: IA EHDI 2009-2012



Lost to Follow-up Rates: IA EHDI, 2009-2012

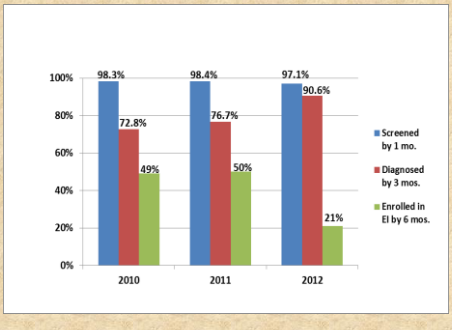


Strategies Used to Reduce Lost to Follow-up (LTF) Rates

- Regular data match with Vital Records to ensure accuracy and completeness of data
- Routine quality assurance checks to maintain high quality of data
- Active follow up on babies who initially miss or refer on their birth screen
- Active follow up on home birth families with a phone number listed in the EHDI database
- Increased primary care provider involvement to encourage PCPs to emphasize importance of timely follow up at the well-child exams
- Encouraging families to make a decision about screening so children don't get marked as lost in the system
- Collaboration with Title V agencies to reduce LTF rates

Data Analysis

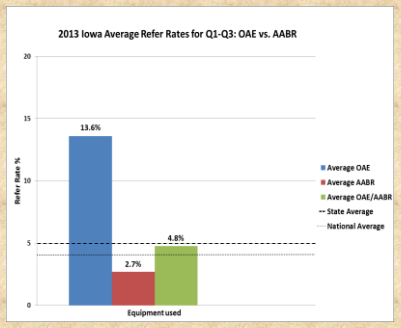
Iowa's 1-3-6 Data for 2010-2012

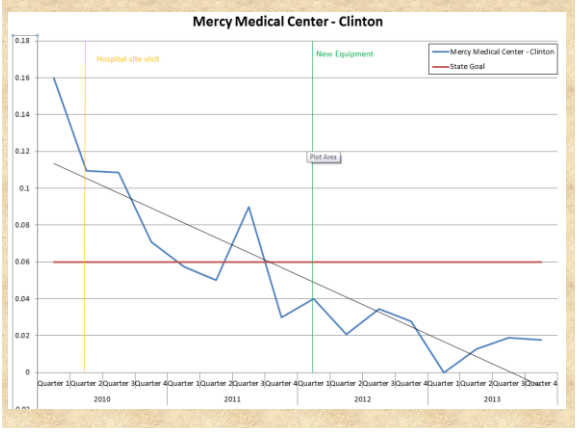


Lost to Follow-up rates by Maternal Demographics; IA EHDI, 2010-2011

Mother's Education Level	2010	2011	Race/Ethnicity	2010	2011
Less than HS	8.40%	7.00%	White	1.10%	0.80%
High School/GED	1.40%	1.00%	Black	1.30%	1.40%
Associate or Bachelors	2.20%	1.90%	American Indian/Alaska Native	1.90%	2.10%
Masters	0.50%	0.50%	Hispanic	1.60%	1.20%
PhD	0.10%	0.50%	Other Races	1.10%	0.95%
Mother's Age	**2010**	**2011**	**Payment Source**	**2010**	**2011**
12-20 years	13%	3%	Private Insurance	0.04%	0.30%
21-29 years	52%	45%	Medicaid	1.60%	1.10%
30-38 years	31%	44%	Self-Pay	9.80%	8.60%
39-48+ years	5%	8%	Other, unknown	2.80%	1.40%

OAE vs. AABR Analysis





Successes, Challenges and Future Efforts

Successes

- Decreased refer rates following training, TA and site visits
- Increased number of providers conducting outpatient (OP) hearing screens from 5 in 2006 to approximately 85 in 2008
- Quarterly hospital progress reports disseminated since 2009
- All hospitals with NICUs screening w/appropriate equipment (AABR) & performing OP hearing screens for infants born at their facility
- Parent on staff to manage Guide By Your Side program/perform FUP
- Established screening programs in Early Head Start programs and two Amish communities
- CDC recognition for program progress since 2006 including hospital site visits and program evaluation activities including parent, database, and primary care provider survey

Successes Cont'd

- Parent(s), Deaf adult(s), and variety of hearing healthcare providers serve on EHDI advisory committee
- Active follow-up by Follow-up Coordinator resulting into improved outcomes based on evaluation
- Quality assurance data base checks completed by IDPH EHDI
- Relationships with bordering states to support referrals and exchange of information to meet the needs of children related to hearing screening and diagnostic assessment (IDPH)
- Improved reporting, timely follow up and system more user friendly due to upgrades to the EHDI database (multiple reports, mother's info, case management module)
- Work with DHS to locate children removed and in foster care
- Developed Loss & Found DVD & Medical Home Toolkit for hearing healthcare providers

Challenges

- Database not integrated with VR and other child health programs (metabolic, CAReS, WIC, immunization, etc.)
- Lack of state funds (program relies on 100% federal funds) and adequate personnel
- Lack of epidemiology staff for data analysis
- ENT/physician and nurse attitudes and beliefs
- Higher refer rates related to lower number of births in some facilities and OAE equipment use
- Missing data (phone number) for home birth families that results in lost contact immediately after sending a letter

Future Efforts

- Increase education re: best practices related to screening, follow up to audiologists, ENTs and primary care providers
- Continue national participation in data analysis projects (LTF, refer rates, themes among lost children)
- Continue technical assistance efforts to decrease hospital refer/miss rates and improve timely OP screens
- Exploring feasibility and cost effectiveness of expanding tele-audiology across the state
- Redesign of EHDI website
- Modify progress reports & publish to challenge hospitals
- Update *Iowa EHDI Best Practices manual*
- Collaborate with Title V & WIC agencies to reduce LTF rates.
- Continue to perform routine quality assurance tasks.

Questions ???

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