The Nebraska EHDI Electronic Data System and Follow-up

Jim Beavers and Jeff Hoffman 2011 EHDI Conference Atlanta, GA

NE-EHDI Data System (ERS-II)

Learning objectives

- 1) List the advantages of integrating hearing records with birth records
- Identify key data needed for adequate tracking and follow-up
- 3) Define important factors to construct a quality assurance report.

Goals

- –Module of Nebraska Vital Records System (ERS-II)
- -Create from birth record
- Collect only data needed for follow-up, quality and reports
- -Minimize time and effort of reporters

-"Work in progress"

Development

- Vital records RFP, contract 2004
- Preliminary planning 2004
- CDC cooperative agreement 2005
- Business analyst 2006
- <u>Screening module 2007 (Rollout)</u>
- Data edits, Audiology module 2008
- Enhanced reports, Risk factors 2009
- Date calculations, Case Summary 2010

ERS-II Description

- Electronic Registration System-II (ERS-II)
 SQL Server Database / Citrix-Internet
- QS Technologies, Inc. -> Netsmart Technologies, Inc
- Three tables (records) for Hearing Information
 - HINFO record (summary record)
 - HSCREENING record (detail record linked to HINFO)
 - HAUDIO record (detail record linked to HINFO)

Hearing Information (HINFO) Summary Record

(> 250 data items)

Populated from birth record

- Birthing facility, baby, maternal demographic information
 Data entered at hospital
- Inpatient and outpatient hearing screening results
- Date of Hepatitis B vaccine (for immunizations)

Data entered by NE-EHDI staff

- "Transfer" screening results / outpatient results
- Diagnostic audiologic evaluations

ERS-II Examples

One **HINFO** record – pass of inpatient hearing screening

Detail Records Linked to HINFO Record:

- Three HSCREENING records details of inpatient events and all outpatient hearing screening events (some data copied to HINFO record)
- One HAUDIO record details of audio evaluation (some data copied to HINFO record)

HINFO Record ("Quick Record")

Facility Name	
Alegent Lakeside Hospital	•
Туре	
HOSPITAL	
City State	📃 NICU (more than 5 days)
Omaha 🔽 Nebraska	
Quick Record of Passed Final Hearing Screening prior to Discharge Date of Final Screening with Pass Result on Both Ears 01/30/2011 Parent Educated about hearing screening, hearing loss, etc? (Y,N) Y	

HSCREENING Detail Record

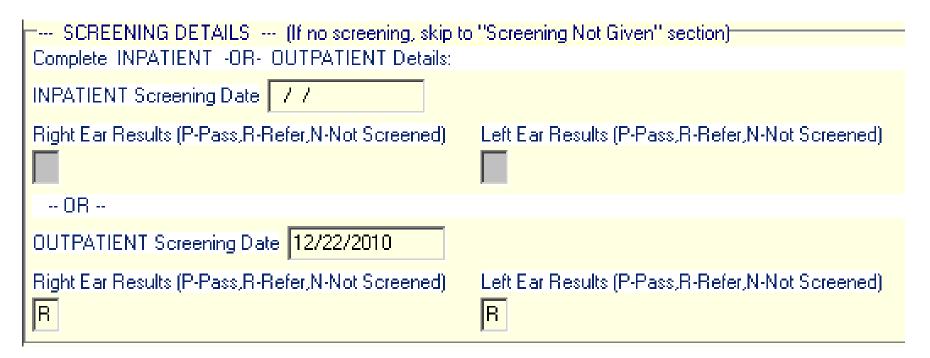
HSCREENING (> 70 data items)

- Inpatient *Refer* hearing screening results
- Inpatient non-screening events
 - Discharge without a screening
 - Refusals
 - Expired
 - Transfers to NICU, other hospital
- Outpatient Pass or Refer hearing screening results
- Outpatient non-screening events

HSCREENING Details Screen Inpatient Refer Right ear

System Details Flags	
FACILITY DETAILS Screening Facility Childrens Hospital ENTER data in SCREENING DETAILS OR SCREENING NOT GIVEN section	Type of Screening
SCREENING DETAILS (If no screening, skip to "Screening Not Given" section) Complete INPATIENT -OR- OUTPATIENT Details:	
INPATIENT Screening Date 12/20/2010	
Right Ear Results (P-Pass,R-Refer,N-Not Screened) Left Ear Results (P-Pass,R-Refer,N-Not Screened) R P 08- 08-	lot Screened)
OUTPATIENT Screening Date 7 /	
Right Ear Results (P-Pass, R-Refer, N-Not Screened) Left Ear Results (P-Pass, R-Refer, N-Not Screened)	lot Screened)

HSCREENING Details Screen Outpatient Refer



HSCREENING – Details Screen Transfer to Another Hospital

MPLETED			
er non-screening action) 12/13/2010			
Outpatient 🔲			
Receiving Hospital (Ctrl + Z to clear the field)			
Childrens Hospital			
Infant in birth hospital NICU > 5 days			
Incomplete Test Code			
6	er non-screening action) 12/13/2010 Outpatient Receiving Hospital (Ctrl + Z to clear the field) Childrens Hospital		

HSCREENING Details Screen (Parent Details, Disposition, Notes)

	one (free form number) ##-###-####	Other Phone
DISPOSITION Primary Care Provider Name (PCP) Allison - Jay R. Allison MD		
 Newborn's Primary Care Provider Notified of results. Recommend monitoring, intervention, and follow up care. 		
Re-screen at same screening facility.		
Recommend re-screen/diagnostic evaluation at audiology clinic.		
Appointment date 12/22/2010 Audiologist/Clinic Boys Town National Research Hospital	•	
NOTES Baby born premature; Father has profound hearing loss;		

HAUDIO Detail Record

HAUDIO (> 200 data fields)

- Facility, audiologist information
- Description of test(s): date, type
- Evaluation results: degree/type/laterality of HL
- Disposition and Recommendations
- Key data copied to HINFO record
 - Initial, most recent, confirmatory results
 - Audio summary, amplification, disposition screens

HAUDIO Record: Evaluation Screen

Evaluation Type	Routine Evaluation
Confirmatory Evaluation	Hearing Loss Normal Hearing
−Right Ear ☐ Not Tested	
Degree of hearing loss* PROF	OUND 🔽
Type of hearing loss . Senso	rineural Hearing Loss 🗾
	▼
Comments (e.g., configuration)	
Left Ear	
Degree of hearing loss* NORM	IAL HEARING
Type of hearing loss	
	▼
Comments (e.g., configuration)	

HINFO: Case Summary (all events)

Parent educated about the	e hearing screening	Hearing Case Sta	tus		Date Closed	Hearing Code 🔲 Non-Hospital Birth
Y		DIAGNOSED		•	11	FD
Birth Facility				Birth Fac	ility City	Birth Facility County
Alegent Lakeside Hospita	I			Omaha		Douglas
Receiving Hospital			Transfer on	Birth Cert	PCP Name Chan	ge #
Childrens Hospital			N		0	
PCP Name - 1st				PCP Nan	ne - 2nd	
Jay R. Allison MD						
PCP Name - 3rd				Transfer	In Transfer Out	
					Y	
-Hearing Status						
Permanent Hearing Loss		efer on OP				
Y	M M	,				
Normal Hearing	Passion IP P	ass on OP				
N	N	I				
-Days to Hearing Event-						
Days to Screening - Pass		Screening - IP Refer	Days to Refer Scr	eening - O	P Refer	
	8		10			
Days to First Evaluation	Days to Confin	matory Evaluation	Days to Last Evalu	uation		
15	18		15			

HINFO – Other Screens

- Mother, Father Identifying Information
- Audiologic Evaluation Disposition Summary
- Audiologic Evaluation Amplification Summary
- Hearing Loss Risk Factors
- Maternal Demographics
 - Age, Marital Status, Education Level, Race, Ethnicity, Payment Source

User Groups / Work Queues

- User groups (5)
 - Super User
 - Administrator
 - Birth clerk
 - Hearing clerk (birth hospital)
 - Hearing clerk (non-birth hospital)
- Work queues
 - Automatic
 - Incomplete records needing data entry

Supplemental Data System

Microsoft[®] Access data system

- Letters to parents and PCPs
- Out-of-state births
- Out-of-hospital births without birth certificates
- Part C data
- Prototype for future ERS-II development

ERS-II Reports

- Birthing Facility Reports
 - Detailed reports (all births at hospital for specified date range)
 - Aggregate reports (by date range using DOB)
 - Number/percent screened
 - Number/percent pass/refers
 - Number not screened and reason
 - Number in NICU
- Administrative Reports
 - Ad hoc reports (Shazam or Report Builder)

ERS-II Data

- Delinquency reports weekly and monthly
- Supplemental data
 - CDC's HSFS annual survey, including all maternal demographics
 - Annual legislative report
 - Periodic reports to NE-EHDI Advisory Committee
- Quality assurance reports
 - Semi-annual reports to birthing facilities
 - Summary statistics for individual facility
 - Includes outcomes, e.g., diagnosed HL, lost to followup, etc.
 - Comparison with state averages

Newborn Hearing Screening Quality Assurance Report (Upper section of report)

Birthing Facility (Jan-Dec	2009 DOB)	Comparison wit	h State Statistics
Type of Hearing Screening – OAE			
Number of live births	1377		
(Percent of Nebraska births 5.1%)			
Expired	1		
Transfers to another hospital	17		
Number available for inpatient screeni	ng 1359		
Number of inpatient screenings	1357		
Percent of screenings completed	99.9%	99.2% - state averag	e of hearing screenings completed
Number of "Passes"		Type of Screening	Average Refer Rate:
Number of "Refers"		2-Step	3.8%
"Refer" rate 10.5%		ABR	2.1%
Inpatient screenings not completed	2	OAE	9.8%
Percent not receiving inpatient screen	ing <mark>0.1%</mark>	.8% - state average	inpatient screening not received
Could not screen 0			
Discharge without screening 2			
Technical problems 0			
Other/Parent Refused 0			
	l	J	

Newborn Hearing Screening Quality Assurance Report (Lower section of report)

Birthing Facility (Jan-Dec 2009)

Percent of parents educated about	
hearing screening, hearing loss and	
speech-language-auditory development	99.9%

Outcomes of Babies Needing Follow-up Services:

144 Needing Follow-up Services	
Normal Hearing :	131
Hearing Loss:	1
Other (in process, expired, moved, refused, etc.) :	2
Lost to Follow-up:	10
Lost to Follow-up rate (10/144) :	6.9%

Comparison with State Statistics

Percent of parents educated about hearing screening, hearing loss and speech-language-auditory development 99.5%

Statewide Outcome Totals:
1,323 Needing Follow-up Services
1,090 - Normal Hearing
39 - Permanent Congenital Hearing Loss
72 - Other (in process, expired, moved, etc.)
122 - Lost to Follow-up
9.2% - "Loss to Follow-up" state average rate (122/1323

Timely, Complete and Accurate Data for All Babies

- Results entered quickly for all births: average is < 12 days
- More detail in ERS-II for all babies needing follow-up:
 - Parent phone number(s)
 - Primary language of parent
 - Primary health care provider (PCP)
 - Outpatient follow-up plans
- Letters and phone calls to PCPs and parents
- Outcomes, maternal demographics, calculation of "number of days" to screenings and evaluations

27,199 births in 2009

1360 newborns needed follow-up

•209 were discharged prior to hearing screening

•1151 did not pass hearing screening during birth admission

998 received one or more outpatient hearing screenings

152 received one or more audiologic diagnostic evaluations

65 received a combination of outpatient hearing screenings and audiologic

diagnostic evaluations

145 did not receive any hearing services or the services were not reported

1127 had normal hearing (outpatient pass, evaluation -> normal hearing)

46 were diagnosed with permanent congenital hearing loss (PCHL)

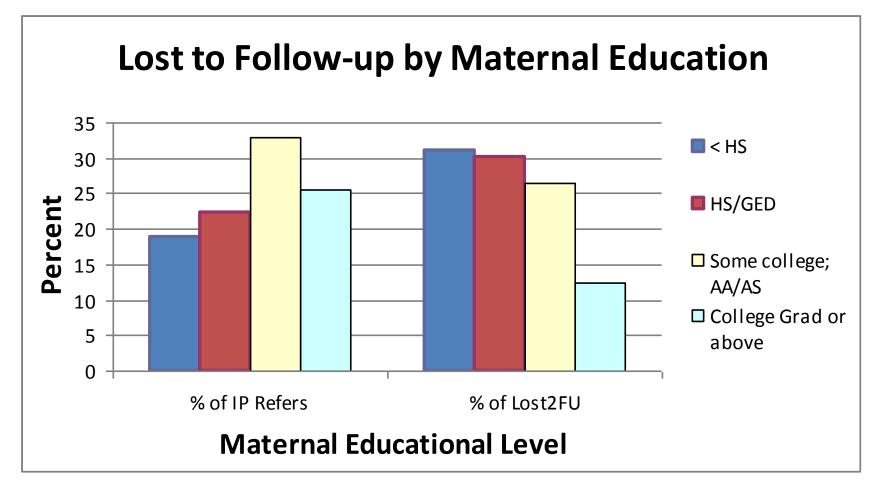
27 are still being evaluated

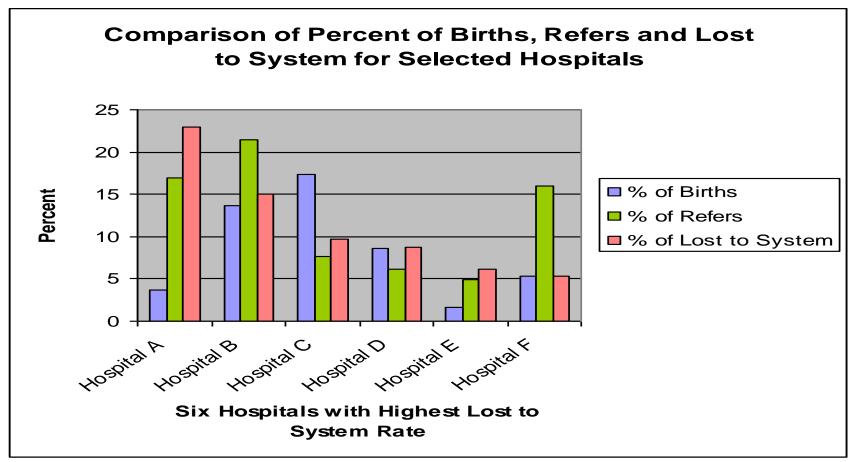
122 were lost to system (did not receive or complete services or services were not reported)

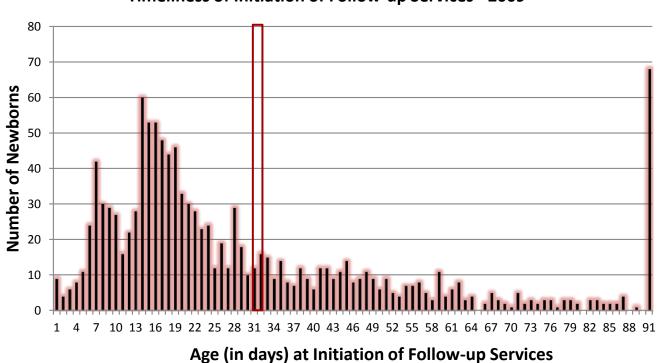
20 families moved with no forwarding address (did not receive or complete services)

14 parents refused prior to outpatient hearing services initiated or completed

4 expired prior to outpatient hearing services initiated or completed







Timeliness of Initiation of Follow-up Services - 2009

NE-EHDI PROGRAM

Kathy Northrop, program manager 402-471-6770, kathy.northrop@nebraska.gov Jim Beavers, program business analyst 402-471-1526, jim.beavers@nebraska.gov Jeff Hoffman, EHDI consultant 402-499-6063, jeffhoffman.ehdi@gmail.com