

Tracking Babies Along the 1-3-6 Journey

The Tennessee EHDI Information System

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The mission of the Tennessee Department of Health is to protect, promote and improve the health and prosperity of people in Tennessee

Learning Objectives

- To assess newborn hearing screening coverage, follow-up tests and intervention services for Tennessee babies
- To identify missed screenings, retests, or intervention and retrieve contact information needed for follow-up
- To provide data related support to the Tennessee Department of Health, Newborn Hearing Screening Program (NHS) and its partners

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Presentation Outline

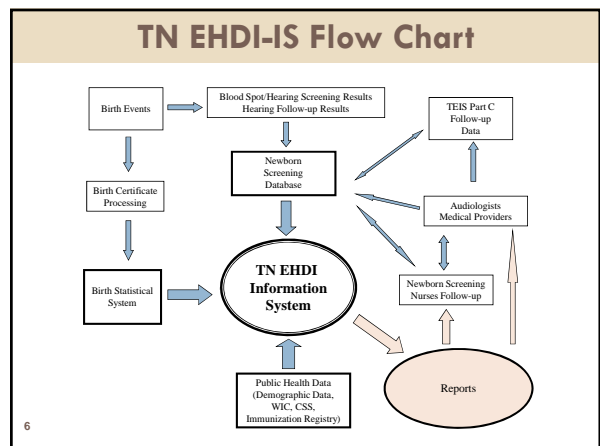
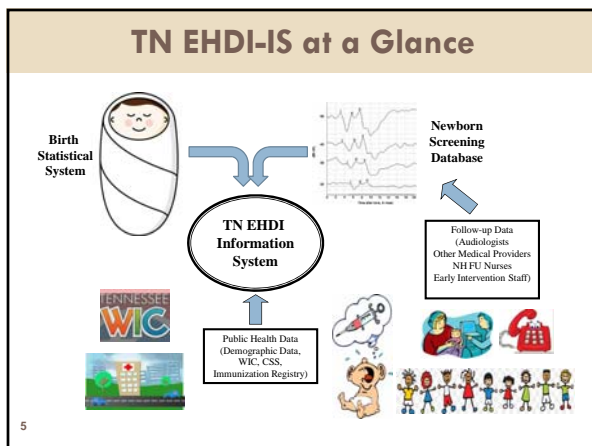
- TN EHDI-IS overview
- Data systems included in the EHDI-IS
- Data linkage process
- Reports generated from the EHDI-IS
- Where TN babies are regarding 1-3-6 goals

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TN EHDI-IS Overview

- CDC EHDI funded since 2008
- Purposes
 - To assess newborn hearing screening coverage, follow-up tests and intervention services for Tennessee babies
 - To identify missed screenings, retests, or intervention; to retrieve contact information needed for follow-up
 - To provide data related support to the Tennessee Department of Health, Newborn Hearing Screening Program (NHS) and its partners

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Data Systems included in EHDI-IS

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- Birth statistical system (BSS)
 - Office of Health Statistics
 - Direct access
 - Daily updates
 - 1,500-2,000 records/week or ~90,000/year
 - No delay in data access
 - 2-4 weeks after birth events

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Data Systems Cont.

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- Newborn screening records
 - Real time, direct access
 - 1,500-2,000 records/week or ~95,000/year
 - No delay in data access
 - No data entry delay when hearing results submitted on blood spot form
 - Some delay if hearing results submitted separately

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Data Systems Cont.

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- Public health data
 - Patients utilizing any health department services
 - Base file generated from birth records
 - Updated at any PH service encounter
 - Immunization
 - WIC
 - Primary care services etc.
 - Children Special Services (CSS) – including diagnosis codes
 - Updated demographic and provider info
 - Used for follow-up
 - Monthly updates since 2012

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Data Linkage Process

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- ~ 90,000 births each year – base cohort for follow-up
- ~95,000 newborn screening records (one baby may have multiple records)
- Birth and screening records are linked on
 - Screening form number
 - Baby's medical record number
 - Mother's SSN and baby's birth order and DOB range
 - Baby's DOB
 - Other variables used for assessing the match
 - Birth order
 - Birth time
 - Child's and mother's last name
 - Mother's resident or mailing address

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Data Linkage Cont.

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- For 2012 births
 - 99.4% birth records linked to NS records
 - Among non-linked records (551)
 - 36% home births
 - 46% died within 7 days of age (including 2 home births)
 - 99.6% NS records linked to birth records
 - Among non-linked records (317 unique children)
 - 12% home births
 - 65% not screened for hearing loss

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Data Linkage Cont.

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- Public health data
 - Birth certificate number provided for most records
 - Updated health care provider information
 - Updated mailing address and/or phone number
 - Diagnosis information - helps pick up some hearing loss cases missed by the NS tracking system
 - Linked to selected birth records
 - Without a hearing screening
 - With referred hearing results
 - Pending or LFU to diagnosis

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Data Linkage Cont.

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- Outcomes from public health data (2012 births)
 - 4,000 + with updated phone number or address
 - Picked up 6 HL cases for 2012 births (85 total)

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Reports from EHDI-IS Data

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- Summary reports on
 - # in-state births
 - # and % hearing screening
 - # and % with hearing loss risk factors
 - # and % referrals
 - # and % hearing loss
 - # and % receiving early intervention
 - # and % lost to follow-up

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Reports Cont.

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- Summary reports grouped by
 - Birthing facilities
 - Primary care/attending physicians
 - Demographic characteristics (maternal race, ethnicity, education, resident county or zip codes, etc.)
 - Method and location of follow-up tests
 - Age (at initial screening, diagnosis, and intervention)
- Formats: PDF; Excel; Crystal Reports – flexible

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2013 Birth Cohort Summary by Birth Place Births, Hearing Screening and Screening Results By Birthing Facilities Outcome = NotPass for HWNL

The FREQ Procedure

Screen_Rate	Frequency	Percent	Cumulative Frequency	Cumulative Percent
100%	4	5.19	4	5.19
95-99.9%	63	81.82	67	87.01
90-94%	5	6.49	72	93.51
70-89%	2	2.60	74	96.10
21-49%	1	1.30	75	97.40
0-20%	2	2.60	77	100.00

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2013 Birth Cohort - with Hearing Screening Age at Time of Screening

Birth Place	Total Screened	Before 1 Month		After 1M Before 3M		After 3 Month		Age Unknown	
		Number	%	Number	%	Number	%	Number	%
ATHENS REGIONAL MEDICAL CENTER	418	416	99.5%	1	0.2%	0	0.0%	1	0.2%
BAPTIST DEKALB HOSPITAL	7	6	85.7%	1	14.3%	0	0.0%	0	0.0%
BAPTIST MEM HOSP-UNION CITY	228	225	98.7%	1	0.4%	0	0.0%	2	0.9%
BAPTIST MEMORIAL HOSP MEMPHIS	4,363	4,284	98.1%	58	1.3%	9	0.2%	2	0.0%
BAPTIST MEMORIAL HOSPITAL-TIPT	417	416	99.8%	0	0.0%	0	0.0%	1	0.2%
BLANCHFIELD ARMY COMMUNITY HOS	1,748	1,732	99.1%	5	0.3%	0	0.0%	11	0.6%
BLOUNT MEMORIAL HOSPITAL	749	749	100.0%	0	0.0%	0	0.0%	0	0.0%
CENTENARIA MEDICAL CENTER	3,044	2,929	96.2%	87	2.9%	24	0.8%	4	0.1%
CLATSOP-COUNTY HOSPITAL	2	2	100.0%	0	0.0%	0	0.0%	0	0.0%
COOKEVILLE REGIONAL MEDICAL	1,526	1,518	99.5%	3	0.2%	0	0.0%	5	0.3%
CROCKETT HOSPITAL	310	306	98.7%	2	0.6%	0	0.0%	2	0.6%
CLATSOP REGIONAL MEDICAL CENTER	637	636	99.8%	0	0.0%	0	0.0%	1	0.2%
DEKALB COMMUNITY HOSPITAL	1	1	100.0%	0	0.0%	0	0.0%	0	0.0%
DYERSBURG REGIONAL MEDICAL CEN	441	436	98.9%	0	0.0%	0	0.0%	5	1.1%
FDH ANSFD FART WOMENS REPRODUCTIVE	3,927	3,921	99.8%	6	0.2%	0	0.0%	1	0.0%
WELLMONT BRISTOL REGIONAL MED	850	845	99.4%	2	0.2%	1	0.1%	2	0.2%
WELLMONT HUNTER VALLEY HOSP	1,091	1,063	97.4%	24	2.2%	3	0.3%	1	0.1%
WILLIAMSON MEDICAL CENTER	1,542	1,536	99.6%	4	0.3%	1	0.1%	1	0.1%
WOMENS WELLNESS & MATERNITY	46	45	97.8%	0	0.0%	0	0.0%	1	2.2%
Total	82,625	81,242	98.3%	1,065	1.3%	151	0.2%	167	0.2%

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2013 Birth Cohort (Failed Initial Screening) - Retest Results by Time at Test Tennessee State Overall Diagnosis Summary - Treating FL Cond. HL as HWNL

	Age Unknown		+1 Month		1-3 Months		3-6 Months		6-12 Months		>12 Months	
	Number	Row Col	Number	Row Col	Number	Row Col	Number	Row Col	Number	Row Col	Number	Row Col
Missing	1,487	85.7 86.8	62	3.6 5.3	88	3.8 8.8	21	1.1 6.6	5	0.3 8.6
HWNL	42	6.6 8.8	1,088	67.2 80.7	815	52.0 60.7	348	18.0 37.1	131	6.6 13.8	44	2.2 4.4
Hearing Loss	2	4.0 5.1	1	1.6 2.0	22	14.0 16.8	17	8.5 17.0	4	2.0 4.0
PENDING	3	3.7 5.2	10	10.0 11.1	36	43.0 47.2	24	12.0 24.0	10	10.0 17.0
PENDING	31	37.6 42.0	16	16.0 17.1	34	29.3 33.2	11	13.4 15.0	1	1.0 1.8
Subtotal	1,546	85.0 100.0	1,167	75.0 100.0	792	51.0 100.0	316	100.0 100.0	151	100.0 100.0	77	8.2 100.0
All Ages												
Missing	1,487	100.0	43.7									
HWNL	1,413	100.0	50.7									
Hearing Loss	46	100.0	1.2									
PENDING	82	100.0	2.2									
PENDING	82	100.0	2.2									
Subtotal	3,774	100.0	100.0									

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2013 Birth Cohort Summary by Birth Place
Births, Hearing Screening and Screening Results
By Birthing Facilities
Outcome - Has/Has Not for HHML

Birth Place	Birth Place ID	Live Births	Hearing Screening Number	Hearing Screening %	Pass	Refer	PAS	Risk	HHML	Confirmed	Fact. Incidence	Lost to Follow-up	Enrolled	Enrolled %
METHODIST MED. CTR. OAK RIDGE	1000001	867	865	99.8%	541	18	0.0%	42	7.4%	0	0.0%	0	0	0
BLOUNT MEMORIAL HOSPITAL	1000002	789	748	94.8%	725	23	2.8%	12	1.6%	12	1.0%	0	132	17.0%
DECATUR MEMORIAL CENTER	1000003	1,138	1,014	89.2%	971	38	3.8%	11	1.0%	0	0.0%	0	1,000	88.0%
UNIVERSITY MEDICAL CENTER	1000004	200	197	98.5%	141	6	3.0%	10	5.0%	0	0.0%	0	197	98.5%
MEMPHIS COMMUNITY HOSPITAL	1000005	449	439	97.8%	411	8	1.8%	12	2.7%	0	0.0%	0	439	97.8%
MEMPHIS REGIONAL MEDICAL CENTER	1000006	367	359	97.8%	311	4	1.1%	6	1.6%	0	0.0%	0	359	97.8%
HARTMAN REGIONAL MEDICAL CENTER	1000007	873	867	99.3%	863	11	1.3%	13	1.5%	0	0.0%	0	867	99.3%
CLARKSBURG MEMORIAL CENTER	1000008	340	337	99.1%	331	3	0.9%	26	7.6%	0	0.0%	0	337	99.1%
METRO INDIANOLA GENERAL HOSP	1000009	484	474	97.9%	450	30	6.2%	6	1.2%	0	0.0%	0	474	97.9%
ST. THOMAS MIDDLETOWN	1000010	2,238	2,177	97.3%	1,930	89	4.0%	38	1.7%	0	0.0%	0	2,177	97.3%
UNIVERSITY OF TENNESSEE MEDICAL CENTER	1000011	4,811	4,557	94.7%	3,810	533	11.1%	201	4.2%	0	0.0%	0	4,557	94.7%
UNIVERSITY OF TENNESSEE MEDICAL CENTER	1000012	1	1	100.0%	1	0	0.0%	0	0.0%	0	0.0%	0	1	100.0%
UNIVERSITY OF TENNESSEE MEDICAL CENTER	1000013	1,187	1,146	96.5%	1,097	50	4.2%	34	2.9%	0	0.0%	0	1,146	96.5%
CENTRAL MEDICAL CENTER	1000014	3,102	3,034	97.8%	2,901	113	3.7%	40	1.3%	0	0.0%	0	3,034	97.8%
BAPTIST DECATUR HOSPITAL	1000015	7	7	100.0%	7	0	0.0%	0	0.0%	0	0.0%	0	7	100.0%
MEMPHIS REGIONAL MEDICAL CENTER	1000016	304	301	99.0%	278	12	4.0%	1	0.3%	0	0.0%	0	301	99.0%
CHICKASAW REGIONAL MEDICAL CENTER	1000017	468	441	94.2%	404	35	7.5%	12	2.6%	0	0.0%	0	441	94.2%
HALLAMER COMMUNITY HOSPITAL	1000018	357	350	98.0%	330	20	5.6%	6	1.7%	0	0.0%	0	350	98.0%
WILLIAMSON MEDICAL CENTER	1000019	1,411	1,408	99.8%	1,379	24	1.7%	6	0.4%	0	0.0%	0	1,408	99.8%
UNIVERSITY MEDICAL CENTER	1000020	849	819	96.5%	797	11	1.3%	17	2.0%	0	0.0%	0	819	96.5%
LANCASTER	1000021	7	7	100.0%	7	0	0.0%	0	0.0%	0	0.0%	0	7	100.0%
TOTAL		85,580	83,794	97.9%	80,157	3,635	4.2%	3,629	4.3%	65	0.0%	1,204	74	87.1%

Crystal Reports - [2013 crystal reports_summary by hospital id.rpt]

Crystal Reports - [2013 crystal reports_summary by hospital id.rpt]

Newborn Hearing Screening
Report by Individual Birthing Hospital

Date of Birth Range: 1/1/2013 - 12/31/2013

1909425 ST. THOMAS MIDDLETOWN

SCREENS:

- Total # Births: 6,238
- Total # Births with a Hearing Screen: 6,183
- % with Hearing Screen: 99.1%
- Total # with Hearing Referred: 67
- % with Hearing Referred: 1.1%
- Total # with Hearing Passed: 6,113
- % with Hearing Passed: 98.0%
- Total # with Risk Factors: 362
- % with Risk Factors: 5.8%

AGE AT TIME OF TEST:

- <= 1 Month of Age: 6,093 (99.3%)
- 1-3 Month of Age: 78 (1.3%)
- > 3 Month of Age: 6 (0.1%)
- Unknown Age: 6 (0.1%)

REASON FOR NO TEST:

- Not screened/Unable to test: 46
- Discharged: 2
- Discharged/Transferred: 1
- Still in Hospital: 1
- Expired: 4

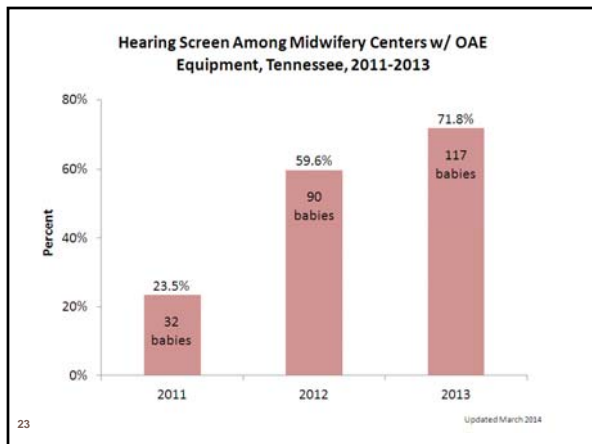
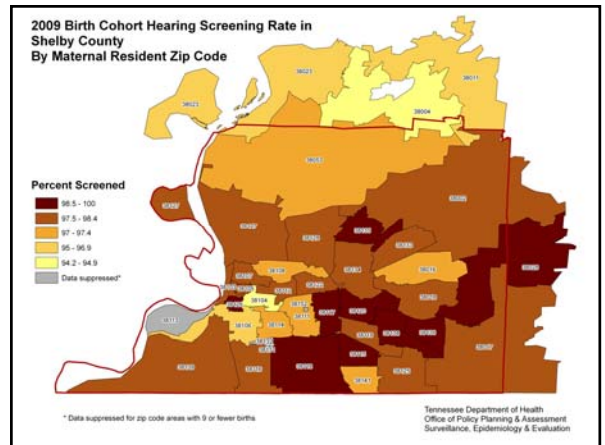
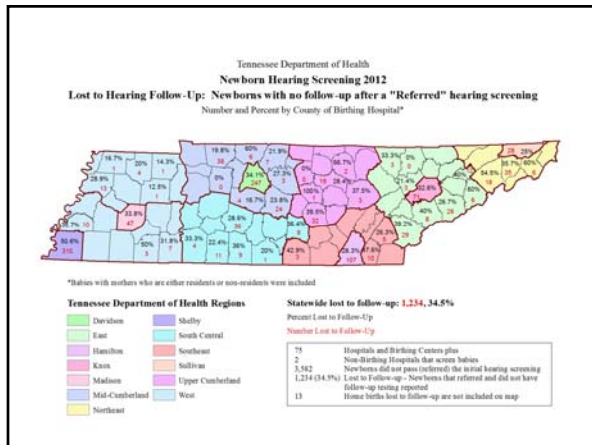
TYPE OF RISK FACTOR:

- Neonatal Indicator: 254
- Symptoms: 1
- Family History: 29
- Craniofacial Anomalies: 13
- In-utero Infection: 0
- Any Risk Factors: 362

TEST METHOD:

- Number of ABR: 6,155 (99.0%)
- Number of OAE: 29 (0.5%)
- Number of Both ABR & OAE: 23 (0.4%)
- Number of Method Unknown: 1 (0.0%)

FOLLOW-UP ON RETESTS AND OUTCOMES

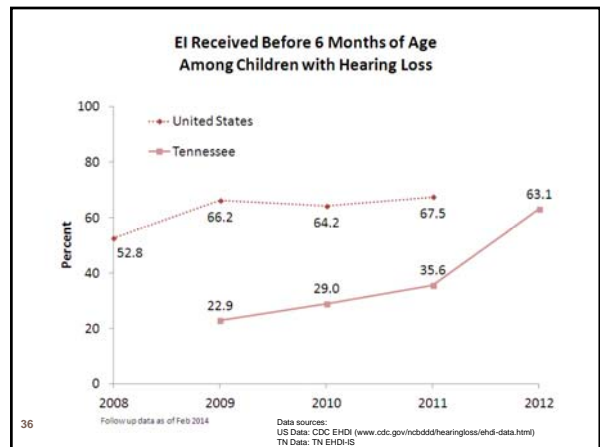
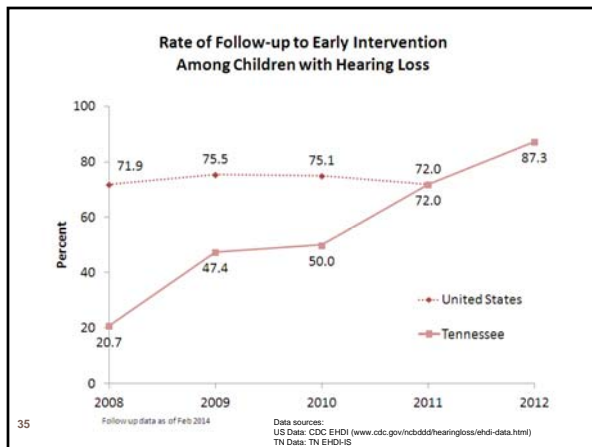
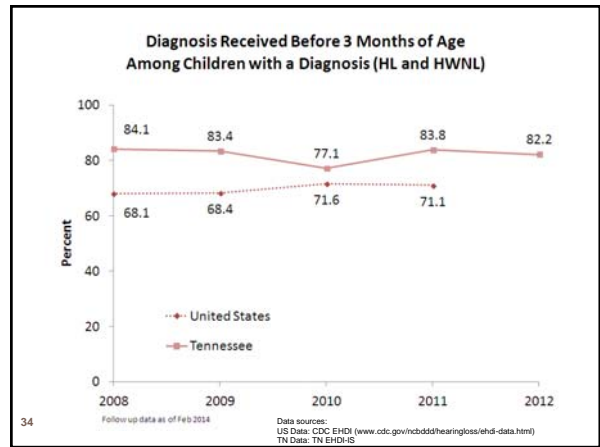
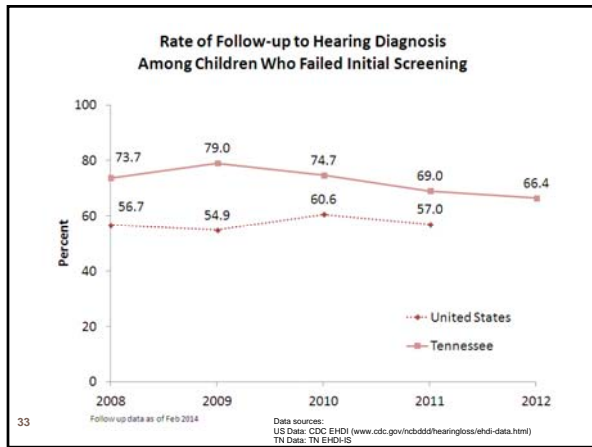
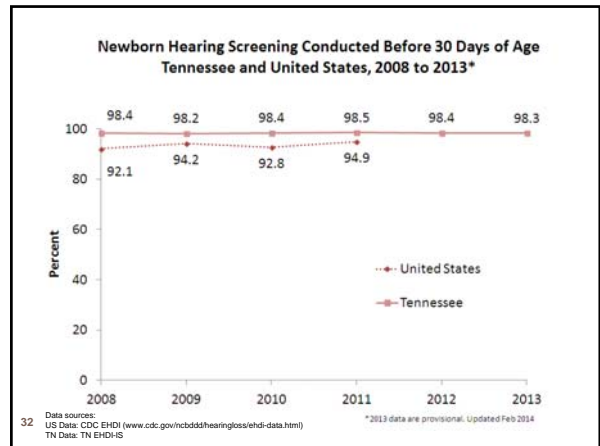
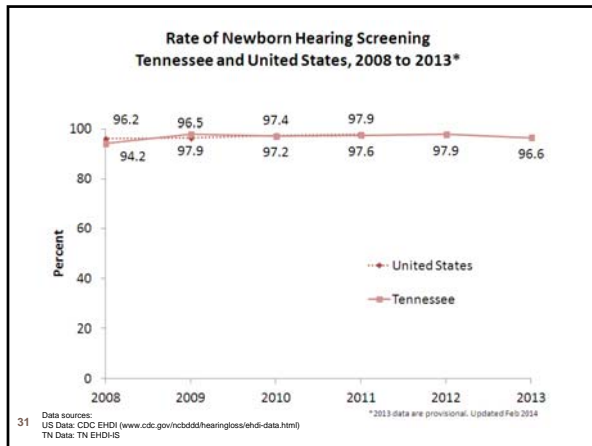


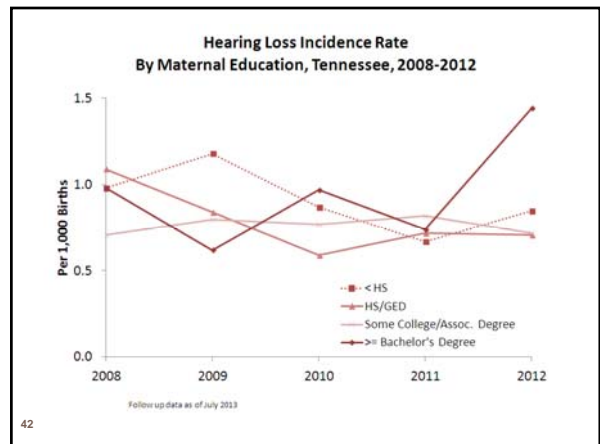
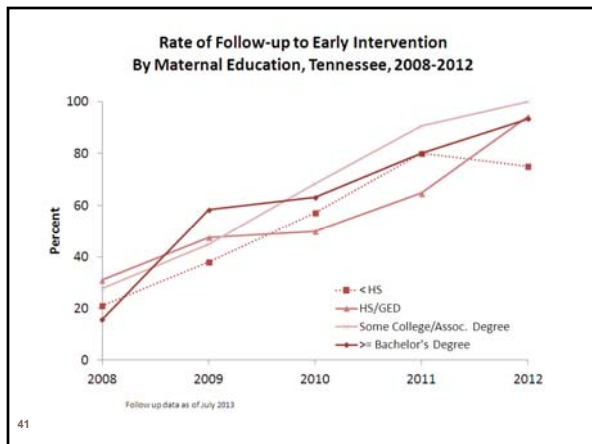
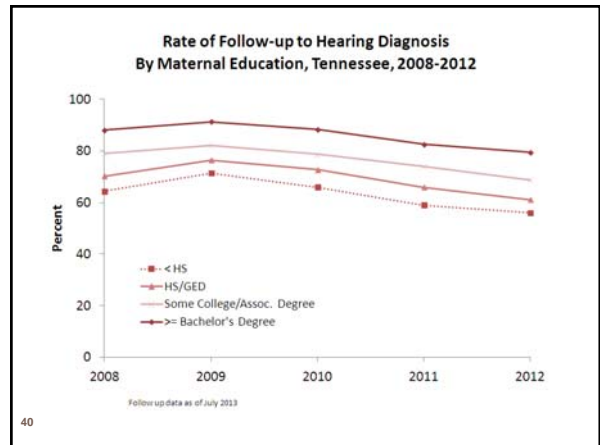
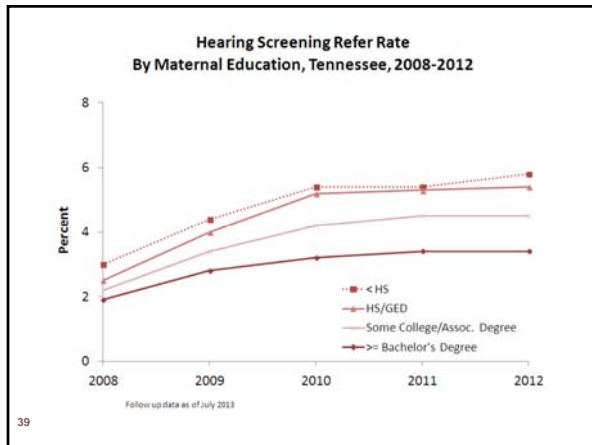
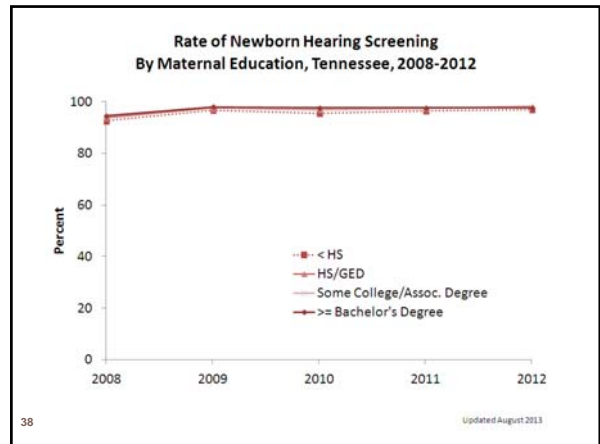
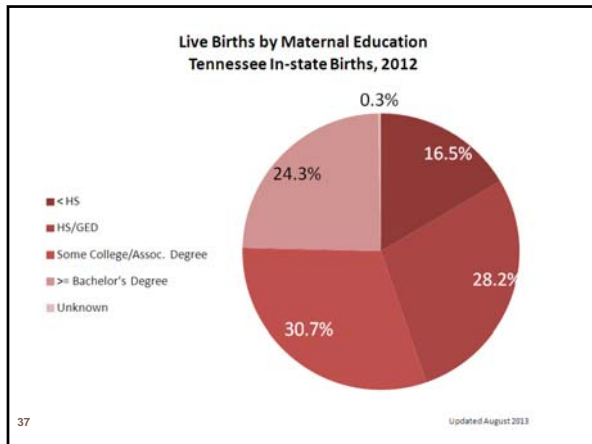
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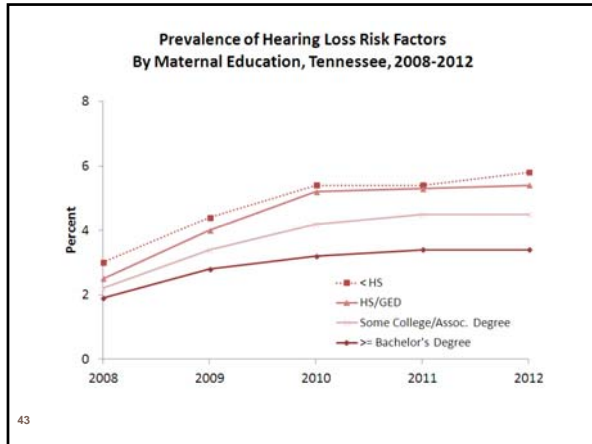
- Individual reports
 - Patient-level information on those who
 - have not received initial hearing screening
 - have risk factors
 - need follow-up tests/diagnosis
 - have confirmed hearing loss

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 - CDC EHDI
- 13th EHDI Meeting, April 13-15, 2014, Jacksonville, Florida

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