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 followup
- To provide data related support to the Tennessee
 Department of Health, Newborn Hearing Screening
 Program (NHS) and its partners

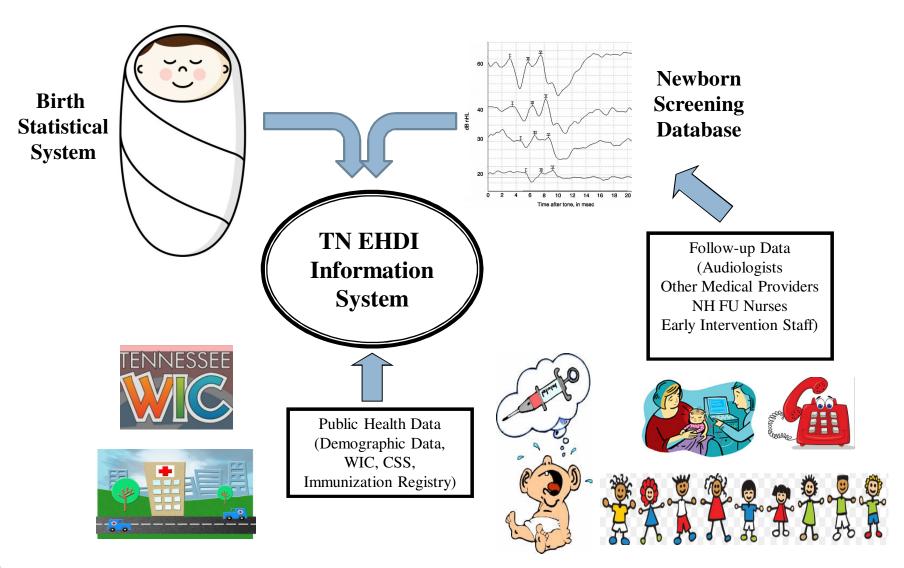
Presentation Outline

- 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

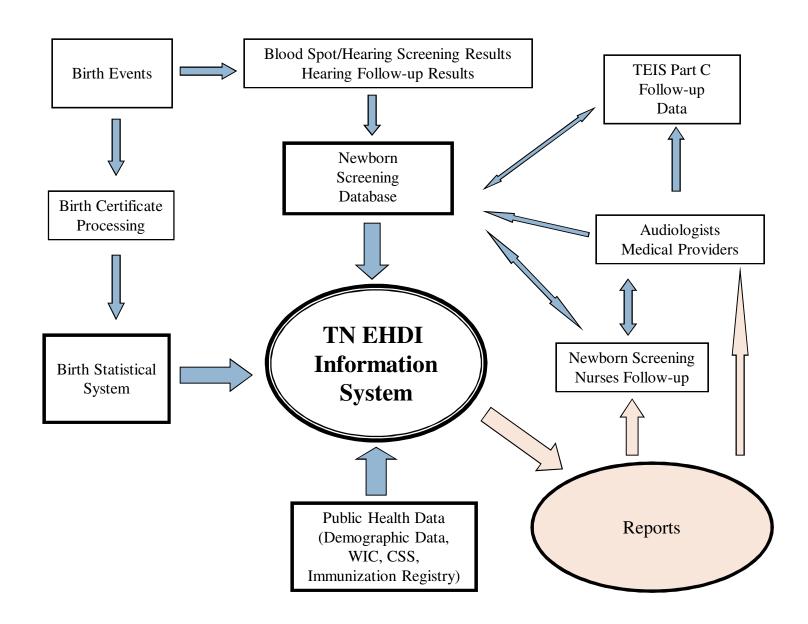
TN EHDI-IS Overview

- CDC EHDI funded since 2008
- Purposes
 - To assess newborn hearing screening coverage, followup 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

TN EHDI-IS at a Glance



TN EHDI-IS Flow Chart



Data Systems included in EHDI-IS

- □ 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

Data Systems Cont.

- 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

Data Systems Cont.

- 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

Data Linkage Process

- □ ~ 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

Data Linkage Cont.

- □ 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

Data Linkage Cont.

- 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

Data Linkage Cont.

- 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)

Reports from EHDI-IS Data

- 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

- 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

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

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

		Before 1 Month		After 1M Before 3M		After 3 Month		Age Unknown		
Birth Place	Total Screened	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	4,353	4,284	98.4%	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	740	748	100.0%	- 0	0.0%	0	0.0%	0	0.0%	
CENTENNIAL MEDICAL CENTER	3,044	2,929	96.2%	87	2.9%	24	0.8%	4	0.1%	
CLAIBORNE 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%	
CUMBERLAND 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%	
FRI ANGER FAST WOMEN'S SERVICES	2 507	2 501	99.8%	5	N 2%	n	በ በ%	1	በ በ%	
WELLMONT DRIVEN DESIGNAL MED	050		00.070	0	0.070				_	-
WELLMONT BRISTOL REGIONAL MED	850	845	99.4%	2	0.2%	1	0.1%			-
WELLMONT HOLSTON VALLEY HOSP	1,091	1,063	97.4%	24	2.2%	3		1		-
WILLIAMSON MEDICAL CENTER	1,542	1,536	99.6%	4	0.3%	1	0.1%	1	0.170	-
WOMENS WELLNESS & MATERNITY	46		97.8%	0	0.0%		0.0%	1		-
	82,625	81,242	98.3%	1,065	1.3%	151	0.2%	167	0.2%	

2013 Birth Cohort (Failed Initial Screening) - Retest Results by Time at Test Tennessee State Overall

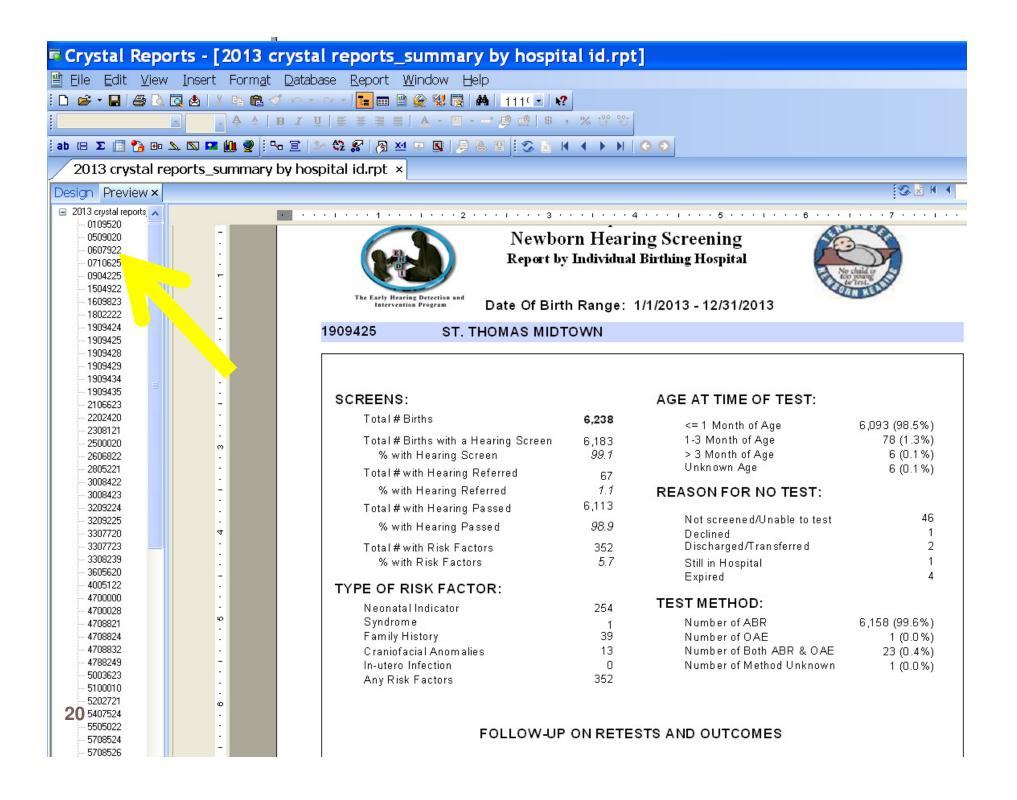
Diagnosis Summary--Treating Fl. Cond. HL as HWNL

							Age at Retest													
Age Unknown <1 Month				1		1-3 Months 3-6 Months						6-	12 Mont	hs	>12 Months					
	Number	Row Percent	Col Percent	Numt	er	Row Percent	Col Percent	Nu	mber	Row Percent	Col Percent	Number	Row Percent	Col Percent	Number	Row Percent	Col Percent	Number	Row Percent	Col Percent
Missing	1,497	90.7	96.9		63	3.8	5.3		65	3.9	8.6	21	1.3	9.6	5	0.3	8.8	-	-	_
HWNL	12	0.6	0.8	1,0	095	57.2	92.2		613	32.0	80.7	149	7.8	68.3	37	1.9	64.9	7	0.4	100.0
HearLoss	2	4.3	0.1		1	2.2	0.1		22	47.8	2.9	17	37.0	7.8	4	8.7	7.0	-	-	-
PEND	3	3.7	0.2		13	15.9	1.1		36	43.9	4.7	20	24.4	9.2	10	12.2	17.5	-	-	-
PENDOTH	31	37.8	2.0		15	18.3	1.3		24	29.3	3.2	11	13.4	5.0	1	1.2	1.8	-	-	-
Subtotal	1,545	40.9	100.0	1.	187	31.5	100.0		760	20.1	100.0	218	5.8	100.0	57	1.5	100.0	7	0.2	100.0

		All Ages	
	Number	Row Percent	Col Percent
Missing	1,651	100.0	43.7
HWNL	1,913	100.0	50.7
HearLoss	46	100.0	1.2
PEND	82	100.0	2.2
PENDOTH	82	100.0	2.2
Subtotal	3,774	100.0	100.0

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

Birth Place	Birth Place ID	Live Births Number	Hearing Screening Number	Hearing Screening %	Pass	Refers	Pct Referred	Risk Number	Risk %	HWNL	Confirmed HL	Fluct. Cond. HL	Incidence per 1,000	Lost to Retest	Enrolled	Enrolled Fluct. HL	Enrolled %
METHODIST MED CTR OAK RIDGE	0109520	567	560	98.8%	541	16	2.9%	42	7.4%	8	0	0	0.00	8	0	0	
BLOUNT MEMORIAL HOSPITAL	0509020	759	748	98.6%	726	22	2.9%	12	1.6%	12	1	0	1.32	9	1	0	100.0%
SKYRIDGE MEDICAL CENTER	0607922	1,119	1,014	90.6%	973	39	3.8%	11	1.0%	18	0	0	0.00	20	1	0	_
JELLICO COMMUNITY HOSPITAL	0710625	200	197	98.5%	191	5	2.5%	10	5.0%	2	1	0	5.00	2	1	0	100.0%
MCKENZIE REGIONAL HOSPITAL	0904225	445	439	98.7%	431	8	1.8%	12	2.7%	5	0	0	0.00	2	0	0	-
NEWPORT MEDICAL CENTER	1504922	187	185	98.9%	177	8	4.3%	6	3.2%	2	0	0	0.00	6	0	0	_
HARTON REGIONAL MEDICAL CENTER	1609823	873	867	99.3%	853	11	1.3%	13	1.5%	4	0	0	0.00	7	0	0	-
CUMBERLAND MEDICAL CENTER	1802222	640	637	99.5%	631	6	0.9%	28	4.4%	3	0	0	0.00	2	0	0	
METRO NASHVILLE GENERAL HOSP	1909424	484	474	97.9%	439	30	6.3%	6	1.2%	4	0	0	0.00	26	0	0	-
ST. THOMAS MIDTOWN	1909425	6,238	6,177	99.0%	6,108	66	1.1%	348	5.6%	35	7	0	1.12	19	5	0	71.4%
VANDERBILT UNIVERSITY HOSP	1909428	4,551	4,357	95.7%	3,810	533	12.2%	515	11.3%	293	10	0	2.20	204	6	0	60.0%
VANDERBILT UNIVERSITY MEDICAL CENTE	1909429	1	1	100.0%	1	0	0.0%	0	0.0%	0	0	0	0.00	0	0	0	-
SUMMIT MEDICAL CENTER	1909434	1,187	1,140	96.0%	1,087	50	4.4%	9	0.8%	24	1	0	0.84	21	1	0	100.0%
CENTENNIAL MEDICAL CENTER	1909435	3,150	3,044	96.6%	3,021	20	0.7%	40	1.3%	9	2	0	0.63	9	2	0	100.0%
BAPTIST DEKALB HOSPITAL	2106623	7	7	100.0%	7	0	0.0%	0	0.0%	0	0	0	0.00	0	0	0	
HORIZON MEDICAL CENTER	2202420	396	391	98.7%	378	12	3.1%	1	0.3%	4	0	0	0.00	8	0	0	
DYERSBURG REGIONAL MEDICAL CENTER	2308121	458	441	96.3%	404	35	7.9%	12	2.6%	18	0	0	0.00	13	0	0	-
VOLUNTEER COMMUNITY HOSPITAL	9204522	357	350	98.0%	330	20	5.7%	6	1.7%	12	0	0	0.00	4	0	0	·
WILLIAMSON MEDICAL CENTER	9402823	1,461	1,406	96.2%	1,379	24	1.7%	5	0.3%	15	5	0	3.42	4	5	0	100.0%
UNIVERSITY MEDICAL CENTER	9508922	849	810	95.4%	797	11	1.4%	17	2.0%	8	0	0	0.00	3	0	0	
UNKNOWN	0000000	- 0	87		79	8	9.2%	26		1	1	0		0	0	0	0.0%
		85,580	83,794	97.9%	80,157	3,585	4.3%	3,829	4.5%	2,082	85	3	0.99	1,204	74	1	87.1%

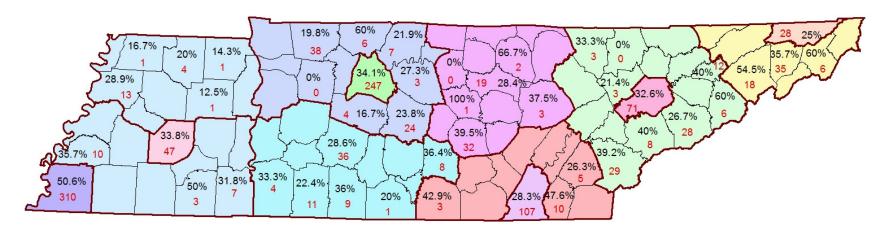


Tennessee Department of Health

Newborn Hearing Screening 2012

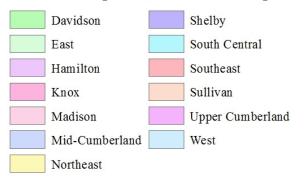
Lost to Hearing Follow-Up: Newborns with no follow-up after a "Referred" hearing screening

Number and Percent by County of Birthing Hospital*



^{*}Babies with mothers who are either residents or non-residents were included

Tennessee Department of Health Regions

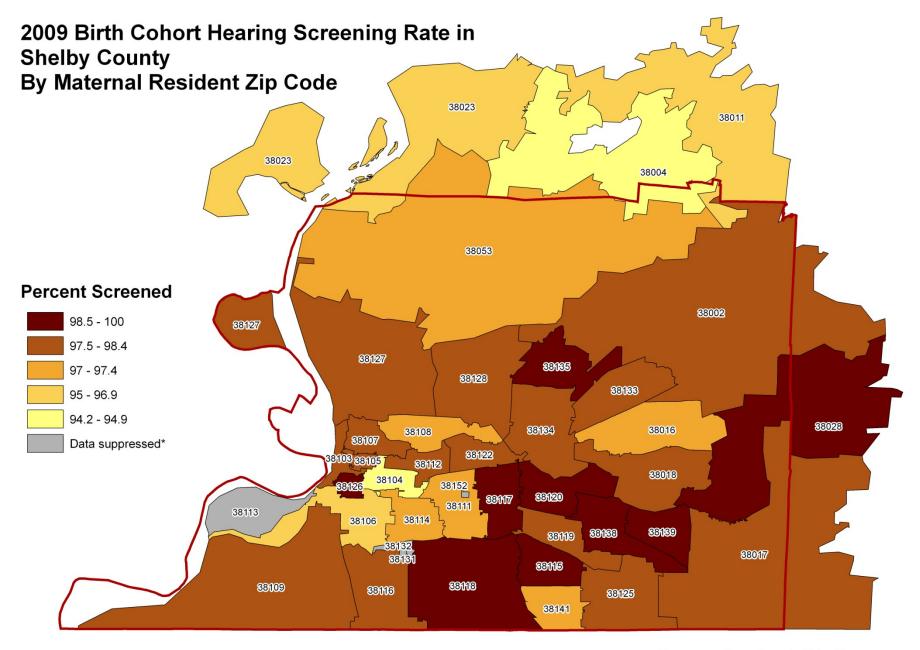


Statewide lost to follow-up: 1,234, 34.5%

Percent Lost to Follow-Up

Number Lost to Follow-Up

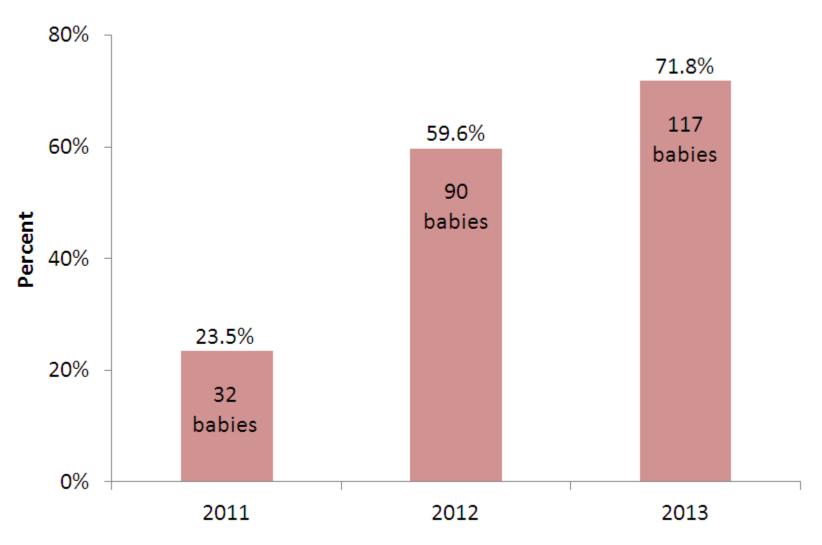
75	Hospitals and Birthing Centers plus
2	Non-Birthing Hospitals that screen babies
3,582	Newborns did not pass (referred) the initial hearing screening
1,234 (34.5%)	Lost to Follow-up - Newborns that referred and did not have
	follow-up testing reported
13	Home births lost to follow-up are not included on map



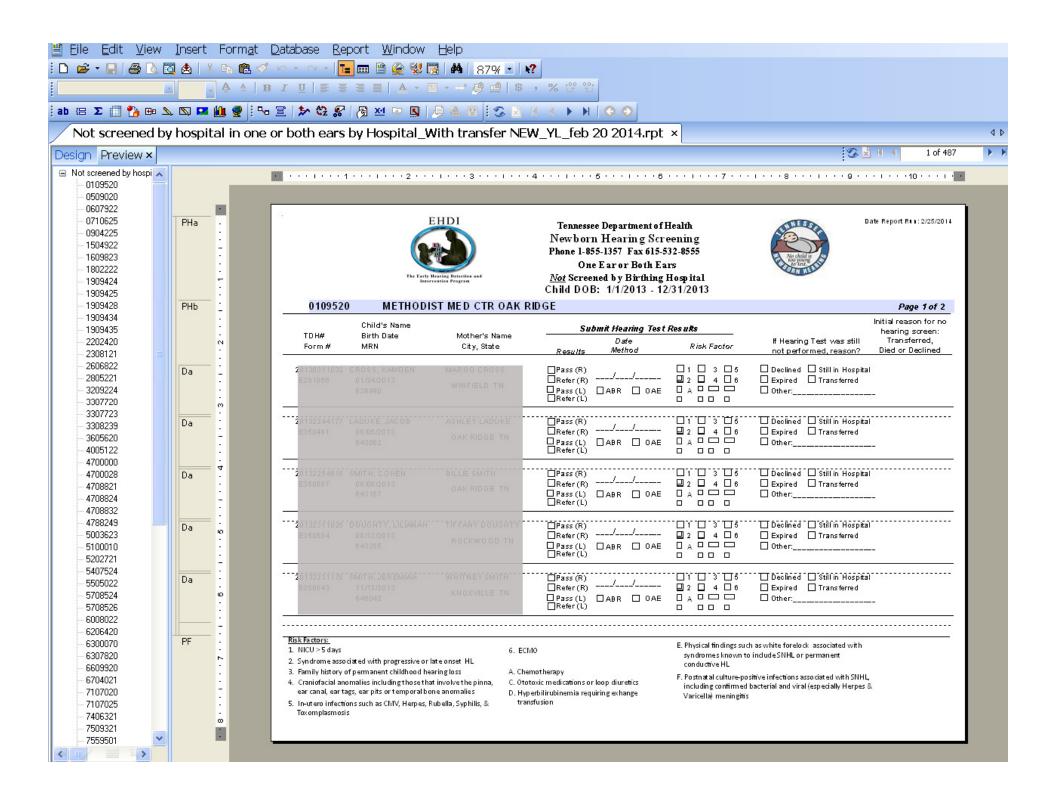
^{*} Data suppressed for zip code areas with 9 or fewer births

Tennessee Department of Health Office of Policy Planning & Assessment Surveillance, Epidemiology & Evaluation

Hearing Screen Among Midwifery Centers w/ OAE Equipment, Tennessee, 2011-2013



- 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



- Data quality control reports: record-level details where
 - initial screening methods are in conflict with screening results
 - hearing test dates are in conflict with child DOB
 - type/degree of hearing loss is in conflict with final diagnosis
 - disposition codes are in conflict with diagnosis codes
 - other potential issues

1 LINK	C dob ABR	L EAR	R EAR	Heardt Screen HT
2 20130084210	01/03/13 1	0	0	01/03/13 Error_Need Check
3 20130084389	01/06/13 2	0	0	01/07/13 Error Need Check
4 20130084391	01/06/13 2	0	0	01/07/13 Error Need Check
5 20130091120	01/05/13 1	0	0	01/06/13 Error Need Check
6 20130111189	01/08/13 1	0	0	. Error_Need Check
7 20130151206	01/10/13 2	0	0	01/10/13 Error_Need Check
8 20130151428	01/07/13 2	0	0	01/09/13 Error_Need Check
9 20130181158	01/14/13 1	0	0	01/15/13 Error_Need Check
10 20130221024	01/19/13 2	0	0	01/20/13 Error_Need Check
11 20130221205	01/17/13 2	0	0	01/19/13 Error_Need Check
12 20130224533	01/20/13 2	0	0	01/21/13 Error_Need Check
13 20130234379	01/21/13 2	0	0	01/22/13 Error_Need Check
14 20130251026	01/20/13 2	0	0	01/21/13 Error_Need Check
15 20130311046	01/24/13 2	0	0	01/25/13 Error_Need Check
16 20130311052	01/24/13 2	0	0	01/26/13 Error_Need Check
17 20130324358	01/29/13 2	0	0	01/31/13 Error_Need Check
18 20130354275	02/01/13 2	0	0	02/02/13 Error_Need Check
19 20130361076	01/30/13 2	0	0	02/01/13 Error Need Check
20 2013033	01/30/13 1	0	0	01/31/13 Error_Need Check
21 2013035	02/04/13 2	0	0	02/06/13 Error_Need Check
22 20130391074	02/04/13 2	0	0	02/05/13 Error_Need Check
23 20130424263	02/06/13 2			02/08/13 Error_Need Check
24 20130451029	02/05/13 2	0	0	02/07/13 Error_Need Check
25 20130451056	02/09/13 2	0	0	02/10/13 Error_Need Check
26 20130501135	02/13/13 2	0	0	02/15/13 Error_Need Check
27 20130511008	02/14/13 1	0	0	02/16/13 Error_Need Check
28 20130521067	02/17/13 2	0	0	02/18/13 Error_Need Check
29 20130591017	02/21/13 2	0	0	02/23/13 Error_Need Check
30 20130591024	02/22/13 2	0	0	02/24/13 Error_Need Check
31 20130634216	03/01/13 2	0	0	03/02/13 Error_Need Check
32 20130641215	02/26/13 1	0	0	02/27/13 Error_Need Check
33 20130644382	03/03/13 2	0	0	03/04/13 Error_Need Check
34 20130661091	03/01/13 1	0	0	. Error_Need Check
35 20130661179	02/28/13 1	0	0	03/01/13 Error_Need Check
36 20130661180	02/28/13 1	0	0	03/01/13 Error_Need Check
H → → H Table 1 - Da	ta Set NEO.FOLLOWUP	2		

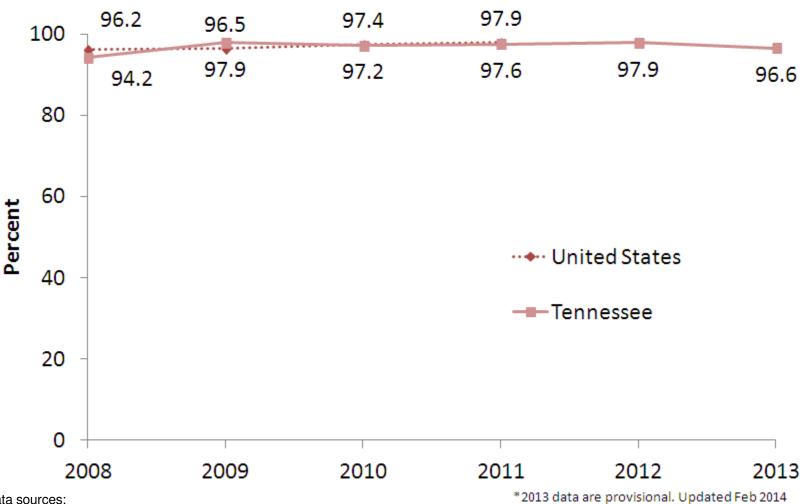
1	PATNO	DIAGCODE	DISPOSITION	Type I	Type r	Degree I	Degree r
2	20120381401		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
3	20120411133		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
4	20120421001		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
5	20120591369		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
6	20121381197		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
7	2012152222		INITYVINL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
8			HEARWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
9			INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
0	20121723312		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
1	20121751176		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
2	20121851313		INITWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
3	20122081005		HEARWNL	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
4	20122131189			Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
5	20123181250		EXPIRED	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limi
16	20123241037		AUTOCLOSH	Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limit
17	20123611434			Within Normal Limits	Within Normal Limits	Within Normal Limits	Within Normal Limi
8	20120811110		NOCNTCT	Inconclusive	Inconclusive	Inconclusive	Inconclusive
19	20121171062		MOVED	Unspecified	Unspecified	Moderate	Moderate
20	20121511266		NOCNTCT	Pending	Pending	Pending	Pending
21	20121681099		NOCNTCT	Within Normal Limits	Pending	Within Normal Limits	Unspecified
22	20121981193		MOVED		Inconclusive		Inconclusive
23	20121991391			Inconclusive	Within Normal Limits	Inconclusive	Within Normal Limi
24	20122421018			Inconclusive	Inconclusive	Unspecified	Unspecified
25	20122484315			Inconclusive	Inconclusive	Unspecified	Unspecified
26	20122491125			Inconclusive	Inconclusive	Unspecified	Unspecified
27	20122491191		MOVED	Pending	Pending	Inconclusive	Inconclusive
28	20122504334		AUTOCLOSH	Pending	Pending	Inconclusive	Inconclusive
29	20122511194		NOCNTCT	Inconclusive	Within Normal Limits	Inconclusive	Within Normal Limi
30	20122623475		AUTOCLOSH	Within Normal Limits	Fluctuating Conductive	Within Normal Limits	
31	20122641030		AUTOCLOSH	Unspecified	Within Normal Limits	Unspecified	Within Normal Limi
32	20122824239		NOCNTCT	Inconclusive	Within Normal Limits	Inconclusive	Within Normal Lim
33	20123121054		AUTOCLOSH	Inconclusive	Inconclusive	Inconclusive	Inconclusive
34	20123321384			Inconclusive	Inconclusive	Inconclusive	Inconclusive
35	20123621373		AUTOCLOSH		Within Normal Limits	Inconclusive	Within Normal Lim
36							The second secon
4	4 N N T 11 4	- Data Set WOR	K.CHECK				

- Report updates
 - Weekly updates
 - Shared on a network drive
 - NHS staff share appropriate reports with partners such as hospitals, audiologists, etc.

Where We Are on 1-3-6 Goals

- Screening rate
 - Percent screened within 1 month of age
- Diagnostic follow-up rate
 - Percent diagnosed within 3 months
- Part C enrollment rate
 - Percent enrolled within 6 months

Rate of Newborn Hearing Screening Tennessee and United States, 2008 to 2013*

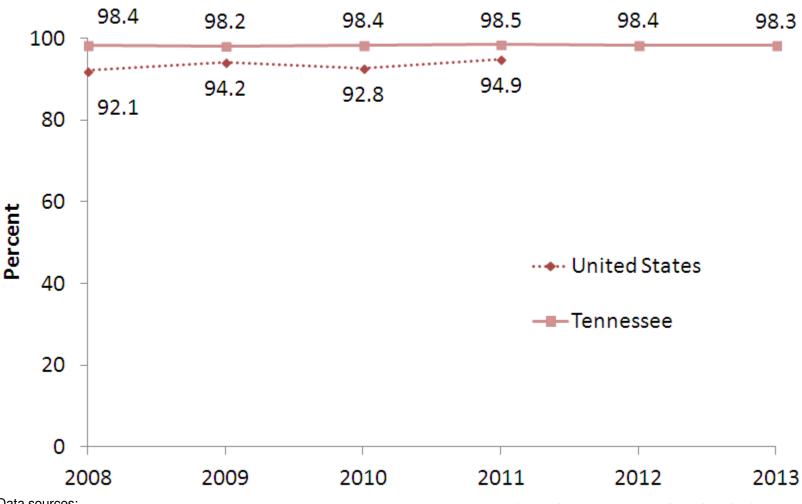


Data sources:

US Data: CDC EHDI (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)

TN Data: TN EHDI-IS

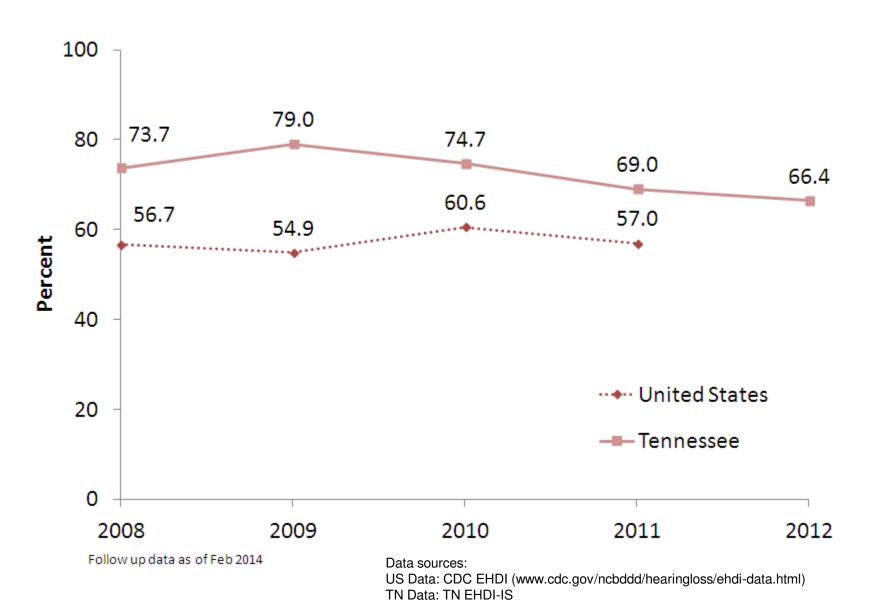
Newborn Hearing Screening Conducted Before 30 Days of Age Tennessee and United States, 2008 to 2013*



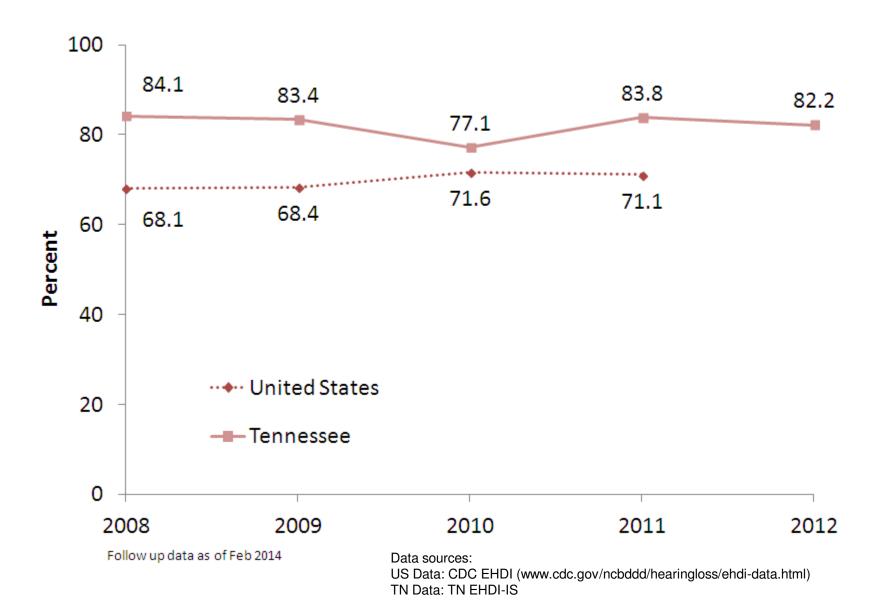
US Data: CDC EHDI (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)

TN Data: TN EHDI-IS

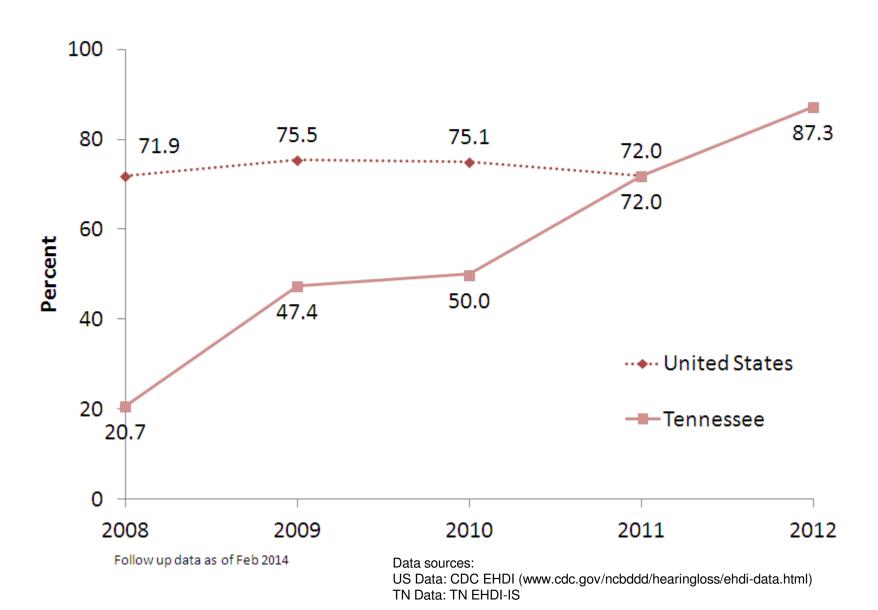
Rate of Follow-up to Hearing Diagnosis Among Children Who Failed Initial Screening



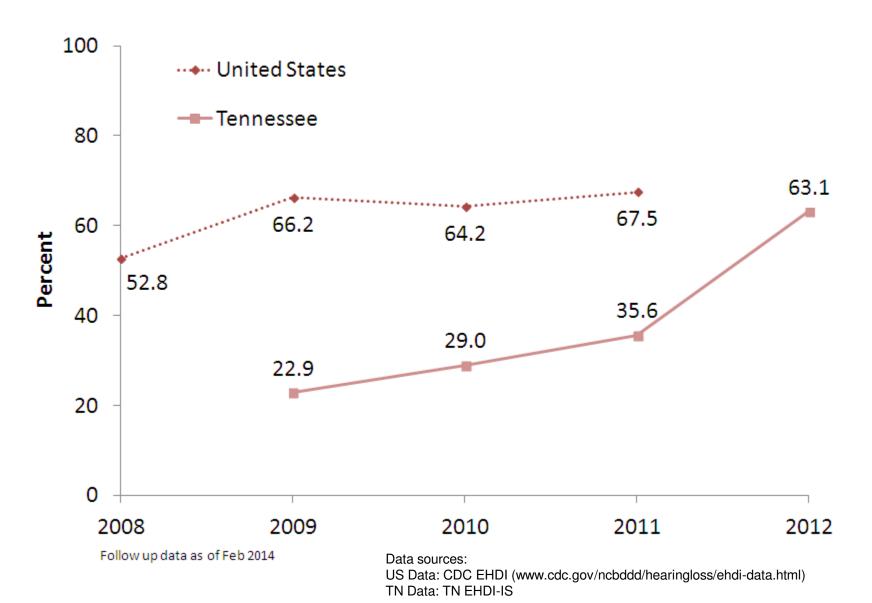
Diagnosis Received Before 3 Months of Age Among Children with a Diagnosis (HL and HWNL)



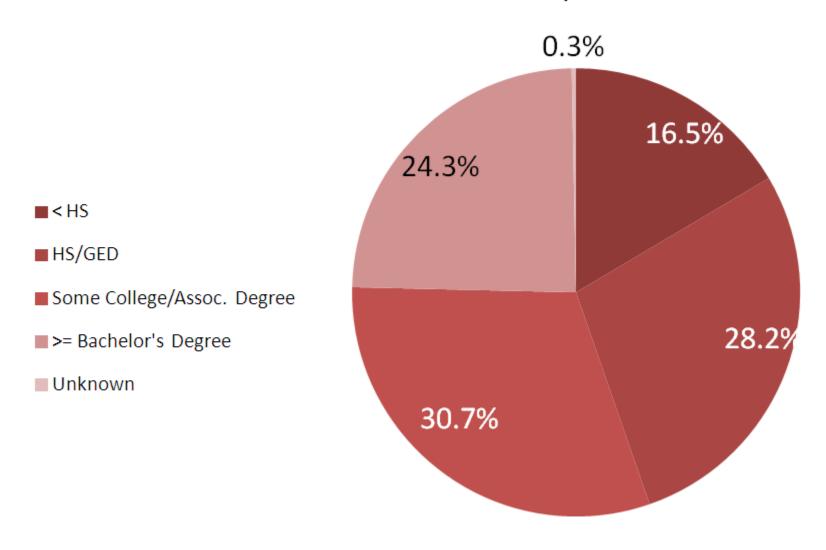
Rate of Follow-up to Early Intervention Among Children with Hearing Loss



El Received Before 6 Months of Age Among Children with Hearing Loss

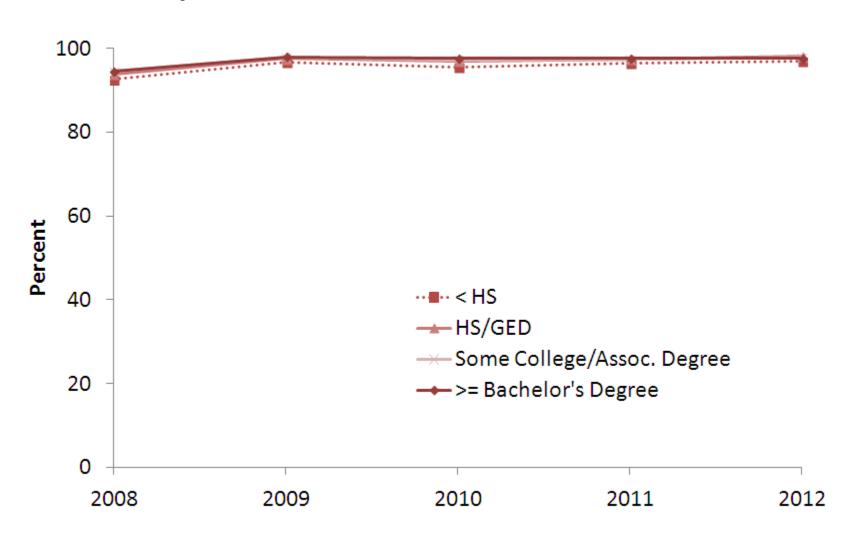


Live Births by Maternal Education Tennessee In-state Births, 2012

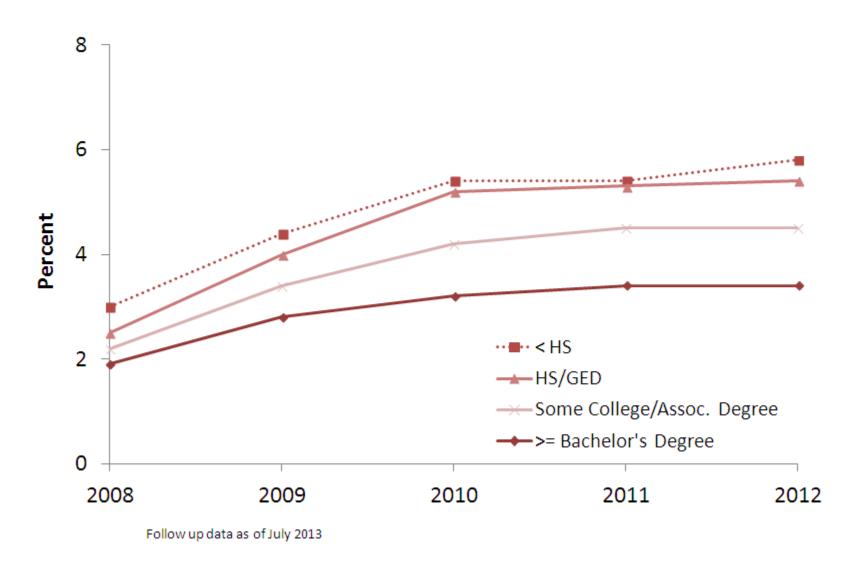


37 Updated August 2013

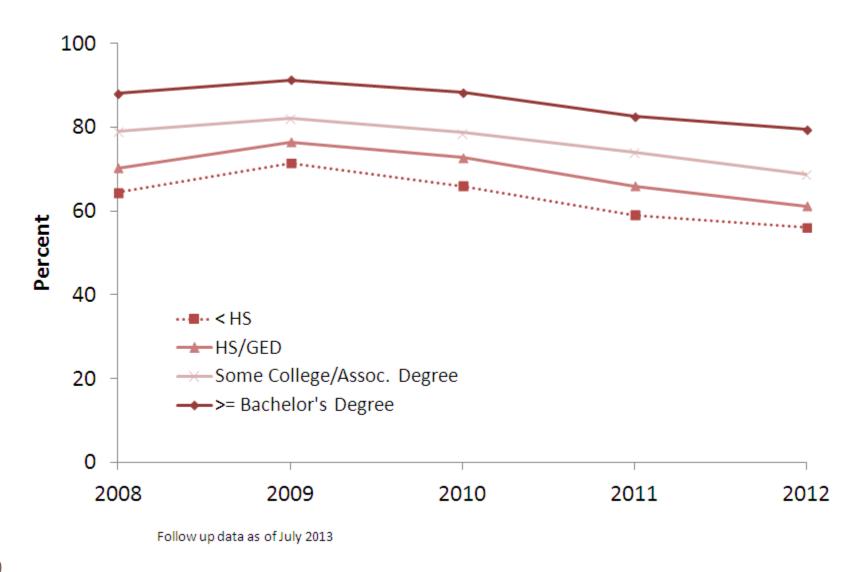
Rate of Newborn Hearing Screening By Maternal Education, Tennessee, 2008-2012



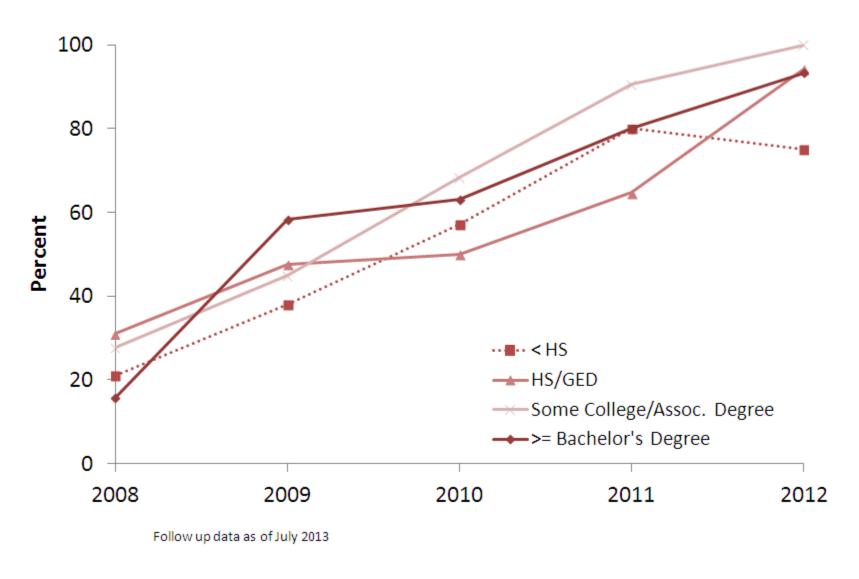
Hearing Screening Refer Rate By Maternal Education, Tennessee, 2008-2012



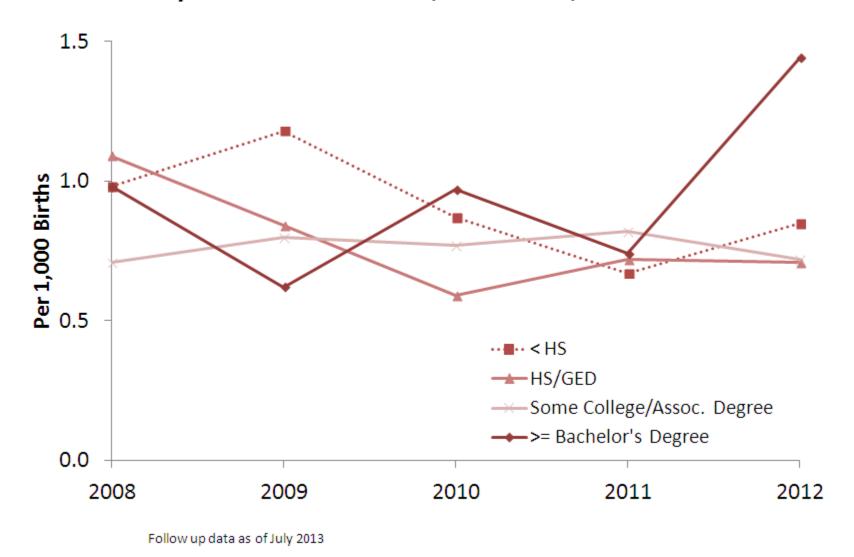
Rate of Follow-up to Hearing Diagnosis By Maternal Education, Tennessee, 2008-2012



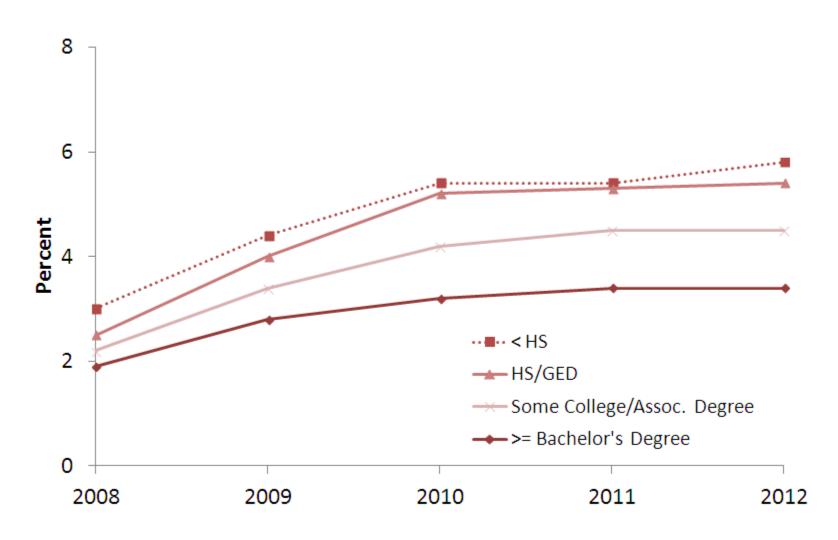
Rate of Follow-up to Early Intervention By Maternal Education, Tennessee, 2008-2012



Hearing Loss Incidence Rate By Maternal Education, Tennessee, 2008-2012



Prevalence of Hearing Loss Risk Factors By Maternal Education, Tennessee, 2008-2012



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