

ii. Project Narrative

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**INTRODUCTION**

The Tennessee Department of Health Newborn Hearing Screening Program requests \$235,000 in HRSA funding to continue and build upon program activities. The Tennessee Department of Health (TDH) Early Hearing Detection and Intervention (EHDI) program is known and commonly referred to as the Newborn Hearing Screening (NHS) program. The program goal is to develop and implement a comprehensive and coordinated statewide system of care so families with newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention.

The TN EHDI program collaborates broadly with partners within the Tennessee Department of Health, other state agencies, non-profit organizations, health care professionals, and families to ensure all infant and children up to three years of age in Tennessee receive appropriate timely services in all aspects of the 1-3-6 journey. The program conducts activities to assure that newborns, infants, and young children up to 3 years of age who are deaf or hard-of-hearing (DHH) receive appropriate and timely services that include hearing screening, diagnosis, and early intervention. The primary objectives for the upcoming four-year cycle of this grant are:

- 1) To increase to 98.4% the percent of infants that completed a newborn hearing screen no later than one (1) month of age, by the end of the four (4) year project period.
- 2) To increase to 85% the percent of infants that completed a diagnostic audiological evaluation no later than 3 months of age by the end of the four (4) year project period.
- 3) To increase to 65.7% the percent of infants identified to be deaf or hard of hearing enrolled in early intervention (EI) services within six months of age by the end of the four (4) year project period.
- 4) To increase by 20% the number of families enrolled in family-to-family support services no later than 6 months of age by the end of the four (4) year project period.
- 5) To increase by 10 percent the number of families enrolled in DHH adult-to-family support services no later than 9 months of age.
- 6) To increase by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI program.

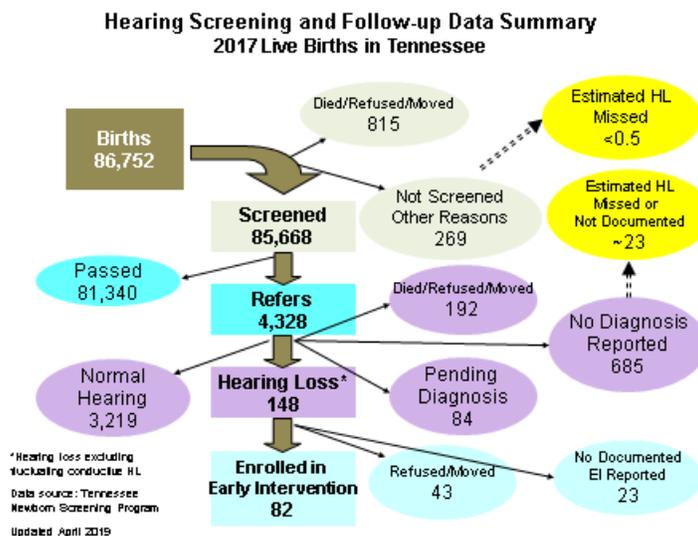
## NEEDS ASSESSMENT

### *Tennessee population overview (US Census Bureau. [www.census.gov](http://www.census.gov))*

According to the US Census Bureau’s estimate, there were 6,770,010 people residing in Tennessee in 2018. The median age was 38.6 per 2013-2017 American Community Survey. 22.2% was children under 18 years of age. 78.5% of the population was white regardless of Hispanic origin; 17.1% was black regardless of Hispanic origin; and the rest (4.4%) were of other races. The Hispanic population regardless of race counted for 5.6% of the total population. 15.0% of the Tennessee population was living under the federal poverty level. Three-fourths of Tennesseans reside in rural areas.

The latest final hearing data available indicate that, in 2017, a total of 86,752 babies were born in Tennessee. Among them, 148 infants were documented with a permanent hearing loss. In addition, it was estimated that another 23 infants had a hearing loss but were not reported to and/or documented in the Tennessee Newborn Screening Program (NSP). These infants were either lost to follow-up prior to diagnosis, or lost to documentation due to re-screen and/or diagnostic results not being reported to the NSP.

The 2012 National Health Interview Survey\* data reported that 15% of US adults 18+ years experienced some hearing difficulty. Assuming the same proportion among Tennesseans, an estimated 800,000 people 18+ years living in Tennessee experience certain levels of hearing difficulty. (\*Blackwell DL, Lucas JW, Clarke TC. Summary health statistics for U.S. adults: National Health Interview Survey, 2012. National Center for Health Statistics. Vital Health Stat 10(260). 2014)



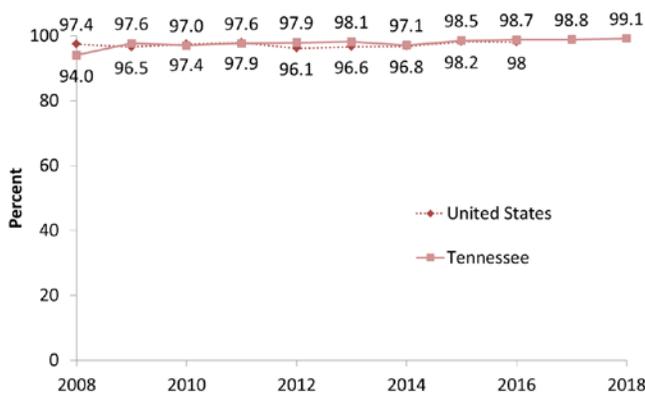
### *Hearing screening and follow-up*

Each year between 80,000 - 90,000 infants are born in Tennessee hospitals, birthing centers and private residences, including resident and non-resident births. The hearing screening rate was 94% in 2008 and it has increased slightly but steadily over time and the rate reached 99% for

2018 births. The screening rate was close to 100% if exclude refusals, deaths and non-residents moving out of the state.

In contrast to the high screening rate, Tennessee’s diagnostic follow-up rate after a failed initial screen fluctuated between 65% and 85% from 2008 to 2018, with the rate being higher than the national rate in most of the years except in 2013. There was a steep drop in 2018, which is still preliminary data and we expect more diagnostic results to be reported in the next few months. Another reason for the drop was the change of the data capture protocol in the TN EHDI data system. TN EHDI data system is designed to capture hearing screening information using a one-stage screening method. In recent years, many hospitals have adopted two-stage screening. For 2018 births, more than 50% of babies were born to hospitals using two-stage protocols. To accommodate such change the program decided to use 30 days from date of birth (DOB) as the cutoff for initial screening, i.e., any results of subsequent tests within 30 days of DOB are entered as initial screening. Such change was implemented in January 2019. This has resulted in a reduced rate of failed hearing screening but has likely increased the loss to follow-up rate for hearing diagnosis since normal results from the diagnostic follow-up tests that were conducted within 30 days of life were not included in the denominator (i.e., total refers) for calculating the loss to follow-up (LFU) rate.

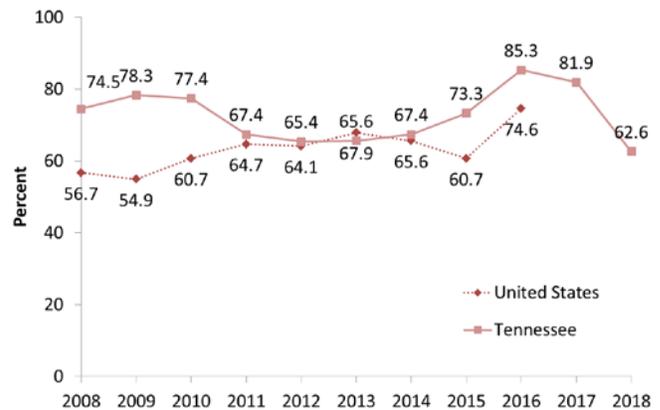
**Rate of Newborn Hearing Screening  
Tennessee and United States**



Data sources: U.S. data were from CDC EHDI; TN data were from TN EHDI-6

Updated Sept. 2019

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



Data sources: U.S. data were from CDC EHDI; TN data were from TN EHDI-6

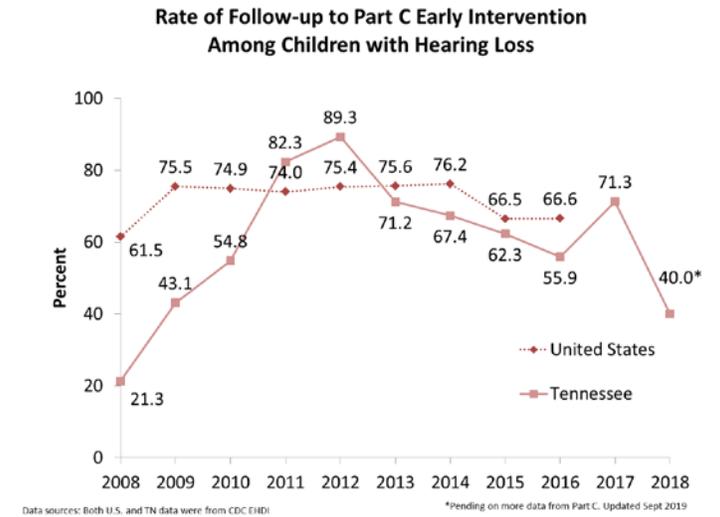
Updated Sept 2019

***Referral to and enrollment in Part C early intervention***

On average about 100 infants were identified with permanent hearing loss each year from 2008 to 2018. All hearing loss cases, including fluctuating conduct hearing loss, were referred to Part C intervention, i.e. Tennessee Early Intervention System (TEIS), which is housed in the Department of Education. They were also referred to Children’s Special Services (CYSHCN) and Family Voices (family support).

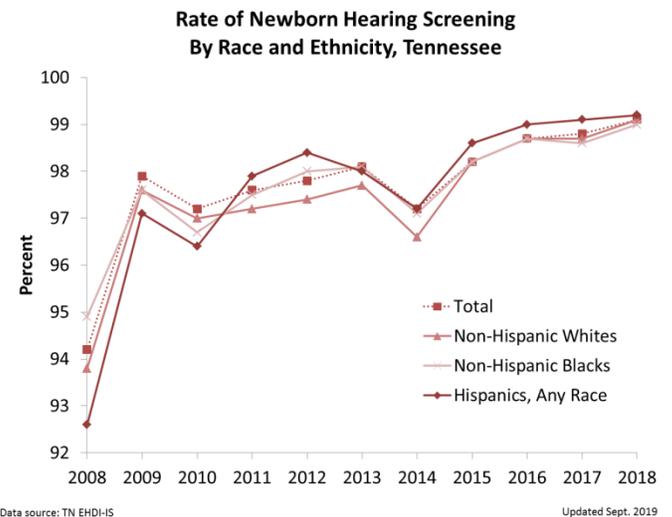
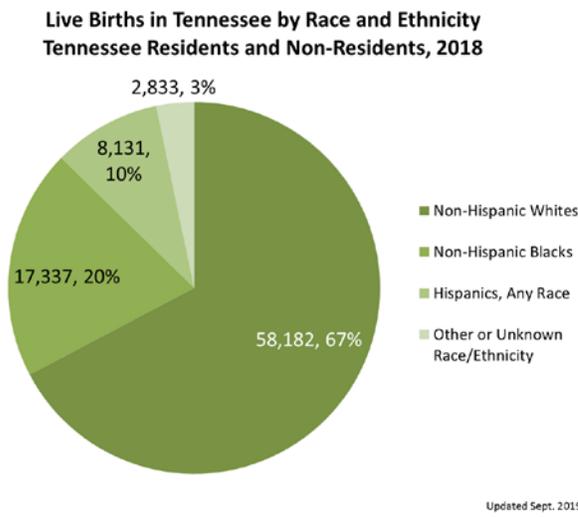
The Part C enrollment rate increased steadily from 2008 to 2012 and then dropped from 2012 to 2016. The drop was largely due to loss to documentation encountered by significant challenges in getting data from TEIS. Starting in January 2018, a new process for data sharing was established and the enrollment data are sent back to TN EHDI on a quarterly basis. Since then

TN EHDI has seen a re-bounce of the enrollment rate for 2017 births. Most of the early intervention (EI) data for 2018 births are still not processed. However, the enrollment rate is expected to be much higher than the current rate of 40%.

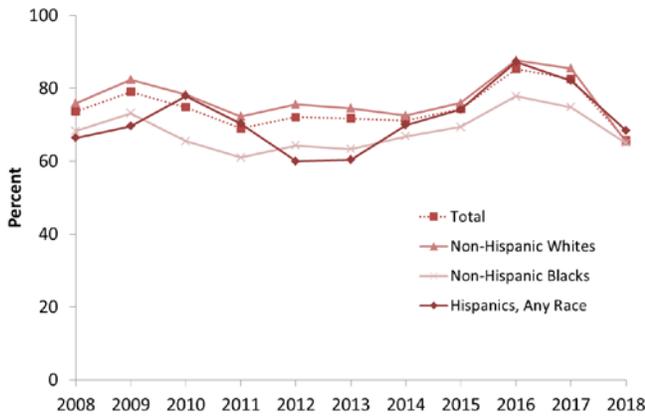


***Hearing statistics by maternal race and ethnicity***

In 2018, 67% of births were born to non-Hispanic white women, 20% to non-Hispanic black women and 10% to Hispanic women of any race. The hearing screening rate and Part C EI enrollment rate were similar among race and ethnicity groups. However, babies born to non-Hispanic black women tended to have a lower rate of hearing diagnostic follow-up after a failed screening compared to babies born to non-Hispanic whites.



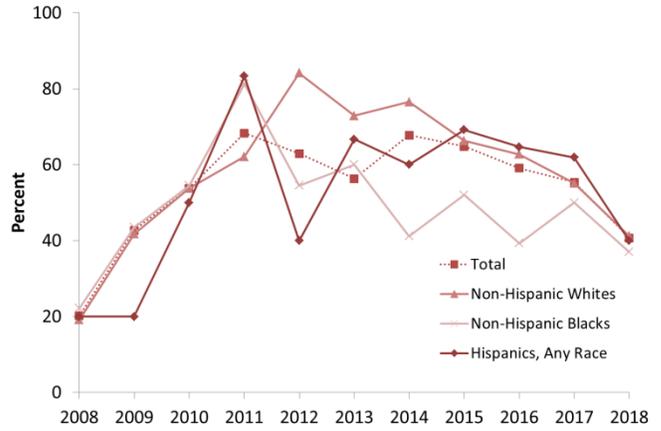
**Rate of Follow-up to Hearing Diagnosis  
By Race and Ethnicity, Tennessee**



Data source: TN EHDH-IS

Updated Sept. 2019

**Rate of Follow-up to Early Intervention  
By Race and Ethnicity, Tennessee**



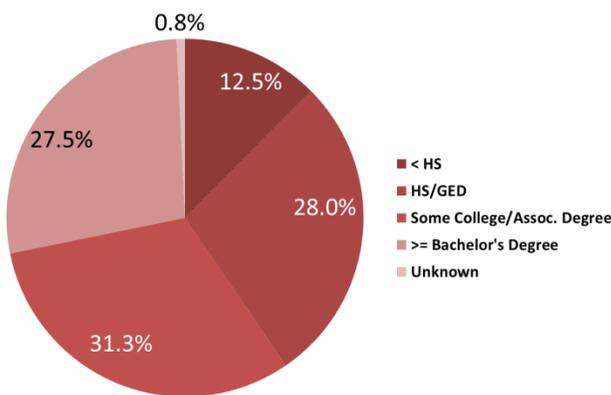
Data source: TN EHDH-IS

Updated Sept. 2019

**Hearing statistics by maternal education**

In 2018, one in eight (12.5%) births was born to women who did not complete high school, about one in 4 (28%) to women with a high school diploma or GED, about one in three (31.3%) to women with some college or associate’s degree, and another one in four (27.5%) to women with a college degree or higher. Infants born to women with less than high school education consistently had a lower screening rate than other groups from 2008-2018, while all other groups had similar rates. The rate of follow-up to diagnostic result after a referred initial screening increased with maternal education level and the pattern was consistent over time. However, the EI enrollment rate fluctuated over time and among groups and no specific patterns of disparities was apparent.

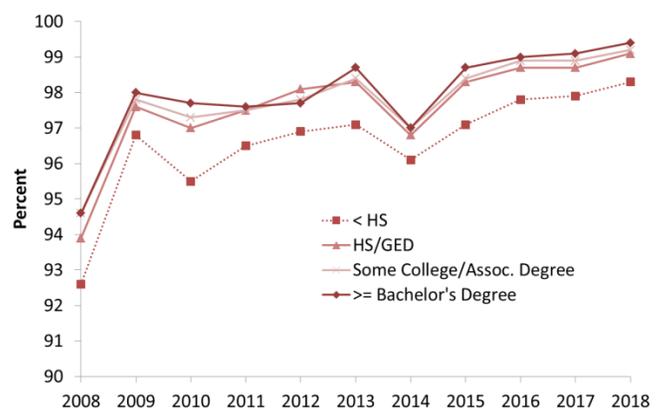
**Live Births in Tennessee by Maternal Education  
Tennessee In-state Births, 2018**



Data source: TN EHDH-IS

Updated Sept. 2019

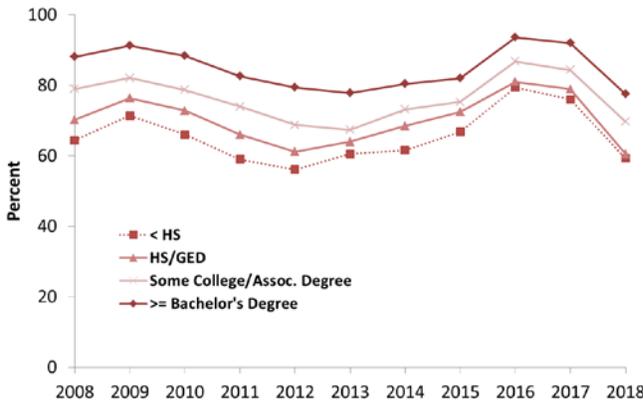
**Rate of Newborn Hearing Screening  
By Maternal Education, Tennessee**



Data source: TN EHDH-IS

Updated Sept. 2019

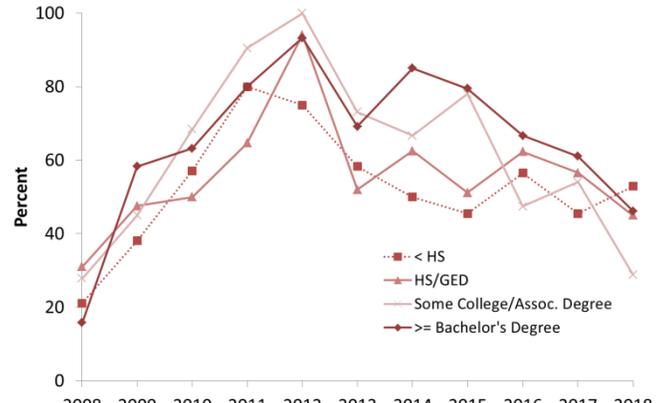
**Rate of Follow-up to Hearing Diagnosis  
By Maternal Education, Tennessee**



Data source: TN EHDI-IS

Updated Sept. 2019

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



Data source: TN EHDI-IS

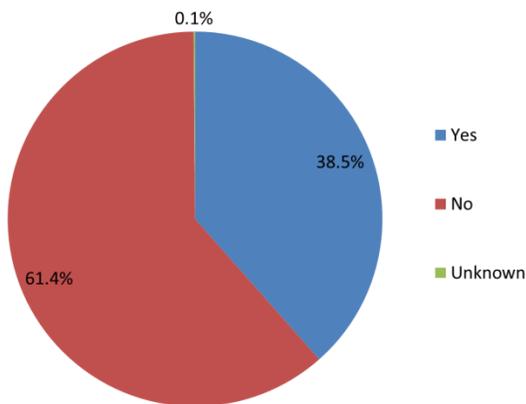
Updated Sept. 2019

**Hearing statistics among infants born to women enrolled in WIC**

The Women, Infants and Children (WIC) Special Supplemental Nutrition Program provides supplemental foods and healthcare support to low-income pregnant, breastfeeding and postpartum women, infants and young children. WIC enrollment serves as a proxy indicator for low income status of the mother. The hearing screening and follow-up data were analyzed by maternal WIC enrollment status at the time of delivery as indicated in the birth certificate data.

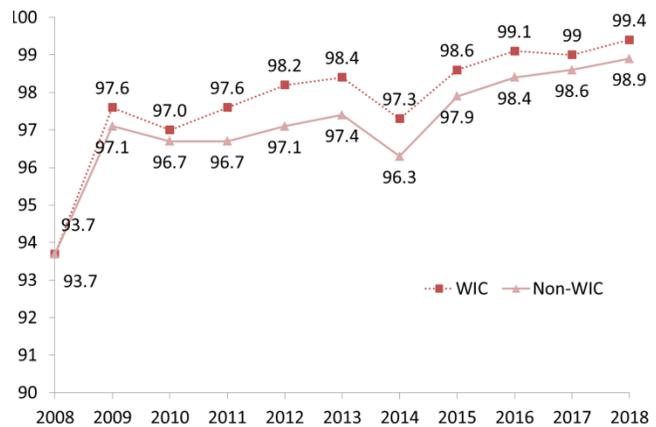
In 2018, 38.5% of births were to women enrolled in WIC. The hearing screening rate was slightly but consistently higher among infants born to mothers enrolled in WIC than those born to non-WIC mothers. In contrast, infants born to women on WIC consistently had a lower diagnostic follow-up rate than those born to non-WIC mothers. The Part C enrollment rate time trend was similar for the two groups.

**Live Births by Maternal WIC Status  
Tennessee Residents and Non-Residents, 2018**



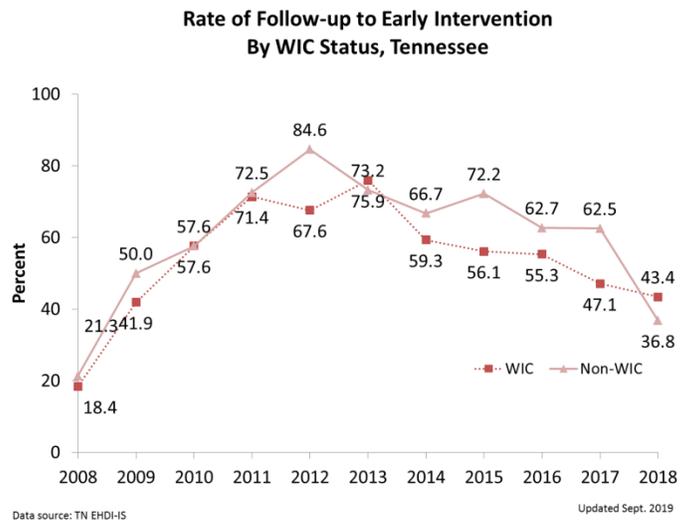
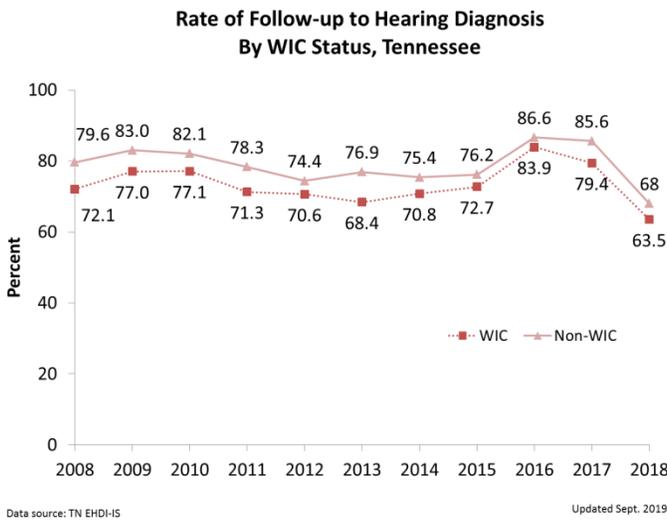
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**Rate of Newborn Hearing Screening  
By WIC Status, Tennessee**



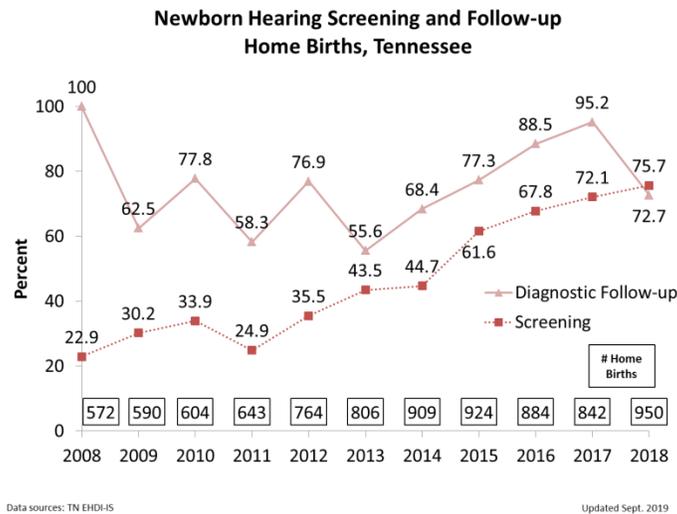
source: TN EHDI-IS

Updated Sept. 2019



**Hearing statistics for home births**

In recent years more Tennessee women chose to deliver their babies at home. In 2008 there were less than 600 (0.6% of all births) home births reported in Tennessee. In 2018 that number increased to 950 (1.1% of all births). The hearing screening rate among home births had increased by 2.3 times from 2008 (22.9%) to 2018 (75.7%). However, this was still much lower than the state rate of 99.1% in 2018. While the screening rate among the home birth population was lower than that among all births, the diagnostic follow-up rate has been similar to those among all births. Six infants were reported to have confirmed hearing loss from 2008 – 2018, among whom three (50%) were enrolled in the Part C early intervention services.

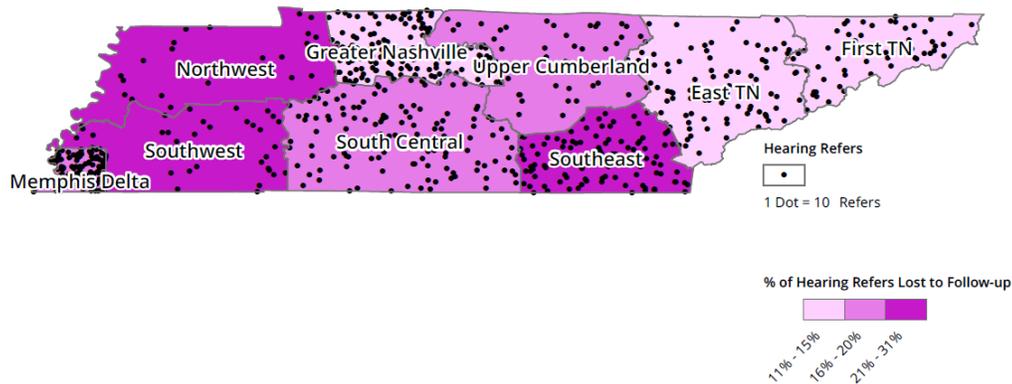


**Hearing statistics by geographic location**

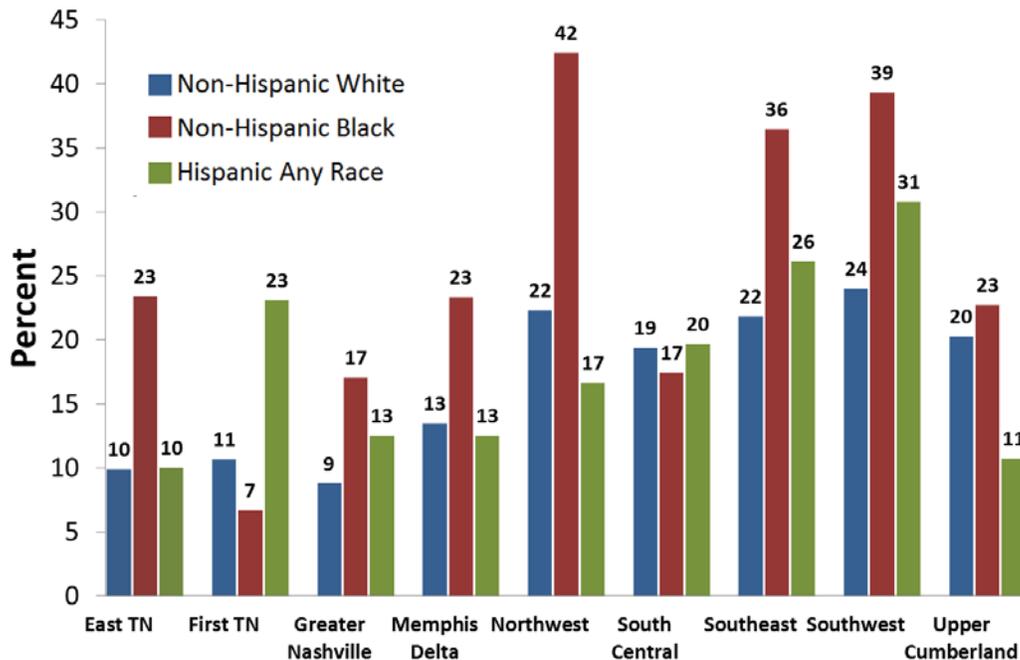
Hearing data were also aggregated by geographic area based on the grouping of counties according to the TEIS district. The screening rate varied slightly from 98.2% for South Central to

99.3% for East TN for 2016 and 2017 births. However, the variations in the LFU rate to diagnosis were much more evident among the nine districts, ranging from only 11% in East TN and Greater Nashville to 31% in Southwest TN. Within each district, with the exception of South Central, there existed disparities among different race and ethnicity groups though the patterns were not consistent across districts. In general, the LFU rate was higher among non-Hispanic blacks than non-Hispanic whites. However, the loss to follow-up rate was higher among Hispanics of any race for First Tennessee. There also existed variations in EL enrollment rate among the districts, with the Part C EI enrollment rate ranging from 48% in First TN to 62% in Upper Cumberland.

### 2016-2017 Loss to Follow-Up and Refers by TEIS District

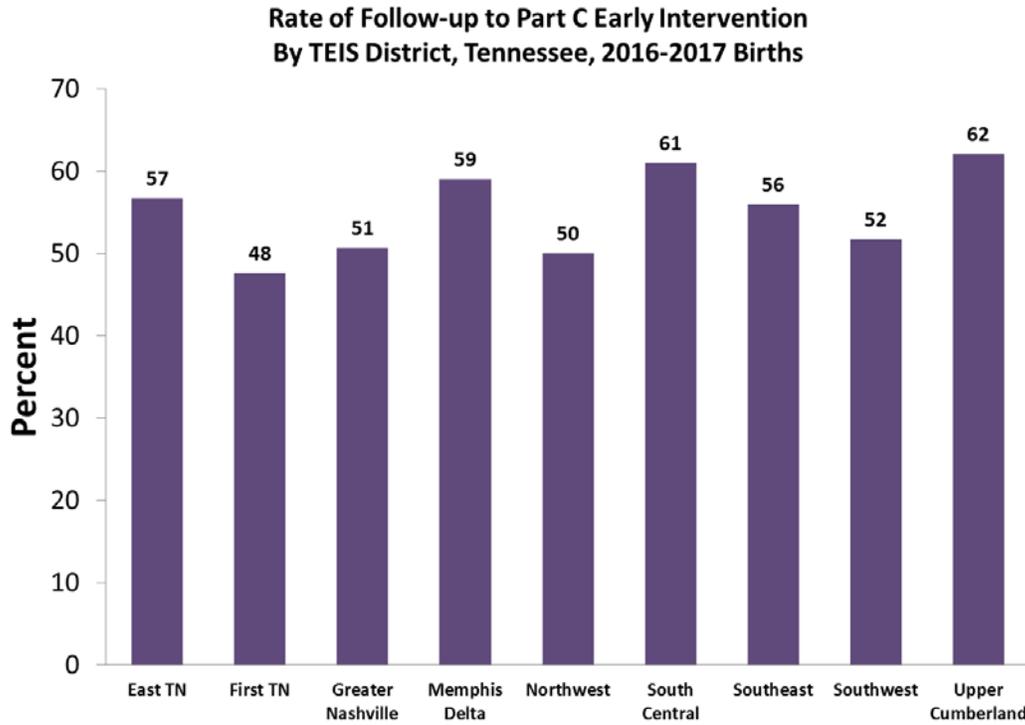


### Loss to Follow-up Rate by Race/Ethnicity and TEIS District Tennessee, 2016-2017 Births



Data source: TN EHDI-IS

Updated Sept. 2019



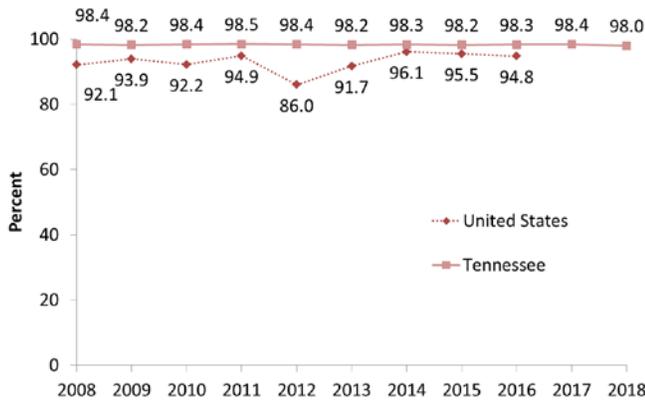
Data source: TN EHDI-IS

Updated Sept. 2019

***TN EHDI 1-3-6 benchmarks***

The hearing data presented so far is hearing data regardless of timeliness. In this section data are presented on the 1-3-6 benchmarks. Among infants who received a hearing screening, 98% of them received screening before 30 days of age and this percentage was consistent over the past 11 years and was slightly higher than the national average. Among infants who completed the diagnostic follow-up, more than a quarter of them had it completed by three months of age, which was higher than the national average. Among infants with a confirmed hearing loss and were enrolled in the Part C intervention, the percent of enrollment before six months of age varied before 2011, then kept stable from 2012 – 2016, being 50% to 60%. The percentage was slightly lower than the national average for most of the years from 2008-2016. TN EHDI saw an increase in 2017 (71.1%) and 2018 (84.7%), though the 2018 data was not complete since more records are expected to be shared back from TEIS.

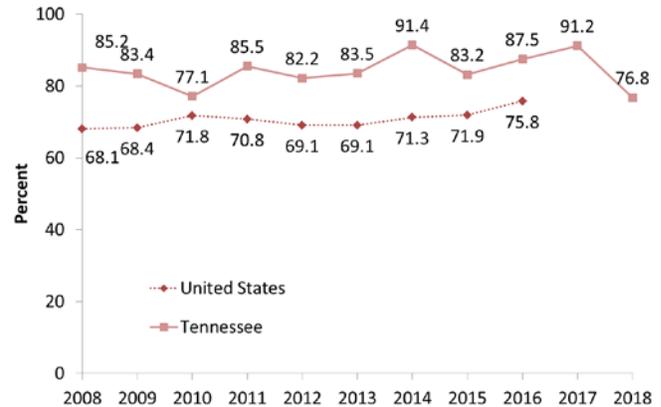
**Newborn Hearing Screening Received Before 30 Days of Age  
Tennessee and United States**



Data sources: U.S. data were from CDC EHD; TN data were from TN EHDI-IS

Updated Sept 2019

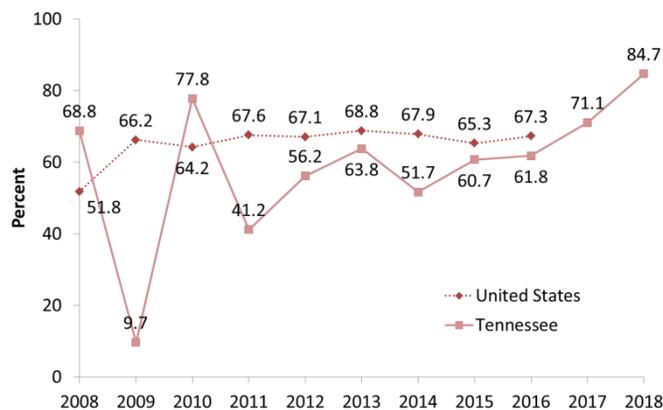
**Diagnosis Received Before Three Months of Age  
Among Children with a Diagnosis**



Data sources: U.S. data were from CDC EHD; TN data were from TN EHDI-IS

Updated Sept 2019

**EI Received Before Six Months of Age  
Among Children with Hearing Loss**



Data sources: U.S. data were from CDC EHD; TN data were from TN EHDI-IS

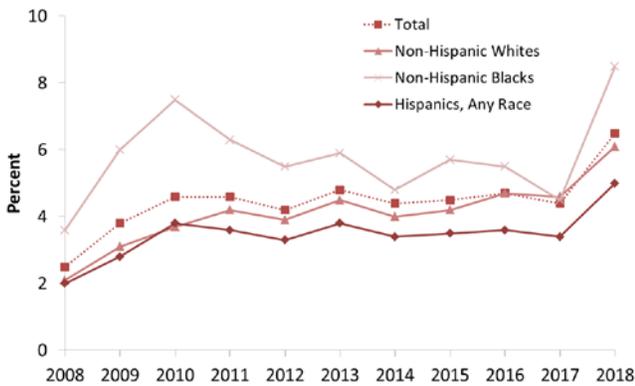
Updated Sept 2019

### Hearing risk factors

The hearing risk factors per Joint Committee on Infant Hearing include being in NICU greater than 5 days, syndromes associated with progressive or late onset hearing loss, family history of permanent childhood hearing loss, craniofacial anomalies, in-utero infection, extracorporeal membrane oxygenation, chemotherapy, assisted ventilation, ototoxic medications or loop diuretics, hyperbilirubinemia that requires exchange transfusion, and physical findings or postnatal culture-positive infections associated with hearing loss (JCIH 2007 Position Statement). The proportion of infants with at least one hearing loss risk factor had been around 4.5% for most of the years for Tennessee births. In 2018 it went up to 6.5%, and the increase was observed for overall population as well as for the subpopulations examined. The recent rise was likely due to the increased awareness and thus increased reporting of hearing risk factors. One of our learning community quality improvement (PDSA) topics in 2018 was on hearing risk factors education among participants.

Babies born to Non-Hispanic black mothers had higher prevalence of risk factor compared to Non-Hispanic whites for all years except in 2017. Hispanics of any race had lower prevalence of risk factors than Non-Hispanic whites from 2011-2018. The risk prevalence had a reverse relationship with maternal education level, with babies born to moms with < high school education having the highest risk prevalence while babies born to mothers with college or higher education having the lowest risk prevalence. Babies born to mothers on WIC also had consistently higher risk prevalence than those born to non-WIC mothers.

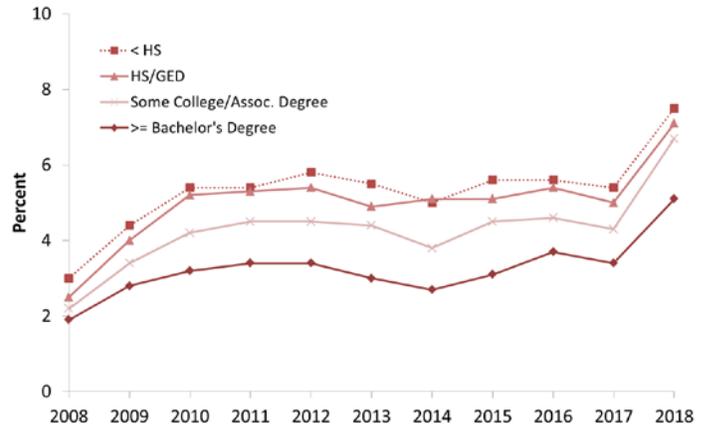
**Prevalence of Hearing Loss Risk Factors By Race and Ethnicity, Tennessee**



Data source: TN EHDI-IS

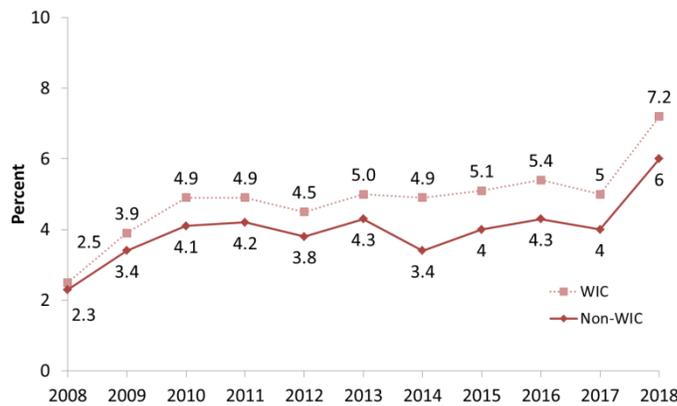
Updated August 2016

**Prevalence of Hearing Loss Risk Factors By Maternal Education, Tennessee**



Updated Sept. 2019

**Prevalence of Hearing Loss Risk Factors By WIC Status, Tennessee**



Data source: TN EHDI-IS

Updated Sept. 2018

**Needs assessment summary**

**General trends:**

Tennessee EHDI continues to improve in key indicators for hearing screening, diagnosis and early intervention. The screening rate was kept high at upper 90% and reached 99% in 2018. The rate of follow-up to diagnosis passed 80% in 2016 and 2017 but expect to drop to some degree due to the change in the data capture method, namely using one stage data system to capture two-

stage screening data. After consistent decline from 2013-2016 due to challenges in receiving intervention data from the Part C partner, the enrollment rate started to bounce back to 71.3% in 2017 after a new data sharing procedure was established in late 2017. The TN EDHI will need to continue to reduce loss to follow-up among infants with a referred initial screening.

**Disparities:**

**Screening:** The subpopulation groups with the lowest screening rate were infants born to mothers with less than a high school education and the home birth population.

**Diagnostic follow-up:** The subpopulation groups with the highest LFU to diagnosis rate were infants born to mothers with less than high school education or enrolled in the WIC program, and the home birth population. Infants born to mothers residing in the Southeast, Southwest and Northwest districts also tended to have a higher rate of loss to follow-up to hearing diagnosis.

**Part C early intervention:** No consistent patterns were observed for EI data for different subpopulations, partially due to the relatively large fluctuations from year to year due to small numbers of children with confirmed hearing loss for the subpopulation.

**Barriers in the service system:**

**Limited access to diagnostic testing:** Subpopulation groups that do not reside in larger metropolitan areas of the state have limited access to advanced diagnostic testing. Monetary constraints often impact the ability for families to travel and access larger hospitals' and clinics' advanced testing resources.

**Professional education:** Providers at smaller regional hospitals and clinics need periodic professional education to stay apprised of the following: 1) Joint Committee on Infant Hearing (JCIH) best practices for hearing screening follow up, 2) reporting results correctly to the Tennessee Department of Health Newborn Screening Program, and 3) incorporating EHDI into the patient and family centered medical home model.

**Diversity of stakeholders that participate in TN EHDI meetings:** Regional task force and Learning Community meetings are attended by professionals in select fields (deaf education, audiology, early intervention) and may negatively impact diversity of thought as quality improvement (QI) projects are regionally sought through Plan, Do, Study, Act (PDSA) activities.

**How barriers in the service system will be addressed:**

**Tele-audiology access:** The TN EHDI program plans to provide tele-audiology services through collaboration with the University of Tennessee Health Science Center. The tele-audiology services will enable families with children with hearing loss to receive up to 3 clinical consultations via video conference with an audiologist or speech pathologist to curtail access to services constraints.

**Education outreach:** The Tennessee Newborn Screening (NBS) program will work with the newborn hearing epidemiologist and quality assurance nurse to identify hospitals that need additional training facilitated by the NBS nurse educator and contracted audiology consultant.

**Integrate diversity among stakeholders that participate in TN EHDI meetings:** The TN EHDI program will seek to enhance the diversity of the stakeholders that attend the regional task force and Learning Community meetings by inviting various stakeholders that represent fields such as WIC, CYSHCN, speech pathology, deaf education, primary care medicine, and early intervention.

## **METHODOLOGY**

### **A. Lead efforts to engage and coordinate all stakeholders in the state/territory EHDI System to meet the goals of the program:**

In Year 1, the program will convene the statewide advisory committee and increase the number of meetings to twice a year. Participants include 25% adults and/or families of those with hearing loss, one dedicated American Academy of Pediatrics (AAP) Chapter Champion, Dr. Mark Gaylord, neonatologist at University of Tennessee Medical Center who provides ongoing consultation, and sixteen (16) additional stakeholders which include EHDI state program staff, TEIS senior leadership, CYSHCN Program Director, WIC Breastfeeding Program Director, four parents of children with hearing loss, one deaf adult, Vanderbilt Mama Lere Hearing School, Audiologists, and a pediatrician. The goal for the advisory committee for the upcoming year will be to facilitate greater collaboration between the program, families, and primary care providers to integrate EHDI in the medical home model in order to identify infants with hearing loss in a more timely way. In addition, we will focus on developing methods to enroll infants in early intervention and family support services sooner to increase the likelihood of their success with speech and language development. In the second year of the new funding cycle, the program will invite additional members for the statewide Advisory Committee based on recommendations collected from current committee members to ensure diversity and inclusion in the EHDI system of care. Members will be invited from our existing regional task force members which currently include representatives from birthing facilities, audiologists, audiology students, speech and hearing centers, Family Voices, Hands and Voices, TEIS, Tennessee's American Academy of Pediatrics Chapter (TNAAP), LEND, West Tennessee School for the Deaf, Memphis Oral School for the Deaf, Tennessee School for the Deaf, and Center on Deafness along with parents of children with hearing loss. Parents have been integral to the success of our program here in Tennessee, and we will emphasize the importance of parent membership and participation in the Advisory Committee in order to keep infants with hearing loss and their families central to our program goals and objectives.

A successful learning community, established in 2017, will expand from a regional meeting to a statewide learning opportunity for health care professionals, early interventionists, service coordinators, parents, and stakeholders over the next project period. The learning community will provide quarterly teleconferences and/or webinars and cover an array of topics related to children recently identified with hearing loss including, but not limited to: 1) Current JCIH 1-3-6 timeline recommendations; 2) Significant risk factors for late-onset early childhood hearing loss; and 3) Providing family-centered care that is culturally competent (reflecting a set of values, behaviors, attitudes, and practices within a system, organization, or program among individuals which enables them to work effectively cross culturally). These recorded presentations/webinars will be maintained and promoted on the tn.gov website to ensure that families have increased access to information as appropriate to make important decisions for their children in a timely

manner. The learning community will develop one PDSA each year to promote peer to peer information sharing within the community throughout the project period. Strategies to address barriers including the integration of the TN EHDI newborn hearing screening data to a core set of other newborn programs including, but not limited to, vital records and blood spot screenings will occur. This activity will facilitate engagement of family partners and health professional perspectives to work collaboratively and integrate differing perspectives. National resources will be embedded to assist in the facilitation of education including the National Centers for Technical Assistance and Family Leadership in Language and Learning. Existing regional task force members from across the state will be invited to participate in the learning community so that education can be promoted within groups across the state and embed information sharing from the learning community into existing regional PDSAs.

Tennessee's successful model of holding annual regional task force meetings in the five current regions (both rural counties and metro counties) – West (Memphis/Shelby County), Northwest (Jackson), Middle (Nashville), East (Knoxville), Southeast (Chattanooga), Northeast (Johnson City) – and quarterly follow up conference calls will be continued. Regional task force representatives consist of birthing facilities, audiologists, audiology students, speech and hearing centers, Family Voices PEARS (Parents Empowerment Access Resources Support), Hands and Voices, TEIS, TNAAP, LEND, West Tennessee School for the Deaf, Memphis Oral School for the Deaf, Tennessee School for the Deaf, Center on Deafness, and parents. For this upcoming grant cycle, intentional engagement and education of early intervention, including Head Start programs, will be a principal program goal. Meeting this goal will include partnering with early intervention staff (in addition to our TNAAP Chapter Champion) in each of the primary regions in Tennessee – West, Middle, and East – to incorporate EHDI goals for children up to age three (3). Each meeting will also include one to two more Family Voices PEARS parent staff partners and/or parents/family members of children or adults with hearing loss. New Family Voices PEARS parent staff will be provided meeting dates and information during their Tennessee Disability Coalition/Family Voices PEARS orientation with the expectation to participate in at least one meeting and one call a year. The program will provide outreach at parent events in order to increase engagement and participation in statewide EHDI activities including the statewide learning community and regional task force meetings. The program will also continue to participate in bi-annual statewide MCHB Block Grant stakeholder meetings in order to network and share ideas with other HRSA-funded programs. These meetings will also provide the opportunity to brainstorm best practices for collaborating with the Family Leadership in Language and Learning Center.

The Tennessee Newborn Screening program will partner with the Early Childhood Hearing Outreach (ECHO) Initiative to focus on extending the benefits of periodic hearing screening to children up to age three (3) in Early Head Start educational programs across the state. The ECHO Initiative is part of the National Center for Hearing Assessment and Management at Utah State University and serves Early Head Start/Head Start programs as the National Resource Center on Early Hearing Detection and Intervention. The contracted audiology consultant will collaborate with ECHO to identify Head Start agencies interested in educating staff regarding the importance of follow up screening and provide technical assistance to interested agencies in performing screenings.

In this upcoming project period the TN EHDI program will reinstate the previously successful Women, Infants, and Children (WIC) records data-matching project. Results for infants that referred on their initial newborn hearing screen but have not completed re-screen services and are at risk of becoming lost to follow-up are matched with WIC records to determine if the infant may be receiving services via a WIC clinic or in one of the Department of Health's home-based care coordination/case management programs such as CHANT (Community Health Access and Navigation in Tennessee). When the infant's parent/guardian visits one of these clinics, the infant's record is flagged as needing hearing screening follow-up. The hearing status of infants from birth to six months of age can then be assessed and the infant can be referred for follow-up as needed.

**Plan of Sustainability:** The Tennessee Early Hearing Detection and Intervention program will continue to engage with the statewide advisory committee in the future to facilitate greater collaboration between the program, families, and primary care providers to integrate EHDI in the medical home model in order to identify infants with hearing loss in a more timely way. The advisory committee has enjoyed unfettered success to date; stakeholders that participate on the advisory committee are dedicated to TN EHDI goals. Similarly, the stakeholders that participate in the TN EHDI Learning Community and in the regional task force meetings are all dedicated to improving the lives of children born with hearing loss and assuring the provision of needed services and support to the families. The Newborn Hearing Screening Program Director will be facilitating all of the aforementioned meetings starting April 1, 2020.

**B. Describe strategies for engaging, educating, and training health professionals and service providers in the EHDI system about the activities described...**

In 2008, Tennessee Code Annotated Title 68, Chapter 5, Part 9 (Claire's Law) mandated that all newborns be screened for hearing at birth. The newborn hearing screening program is responsible for assuring all infants born in Tennessee receive a hearing screening before discharge or prior to one month of age. Ongoing outreach and education with birthing hospitals and contracted newborn screening programs (Pediatrix, Peloton, & Mednax) will be completed to ensure that newborn hearing screening results are being reported timely to the Tennessee Department of Health. The quality improvement staff includes a nurse educator who will collaborate with the contracted audiology consultant over the next project period to provide statewide education, trainings, and technical support regarding the 1-3-6 month goals.

Tennessee newborn screening data are captured in the Neometrics Data System (NDS). Staff have real time, direct access to NDS. On average, about 2,000 new records are added into the system per week. The screening data are collected on the Dried Blood Spot form that includes information for hearing screening, and entered into the NDS by staff at the state laboratory. The system has the capability to capture demographic data and generate follow-up actions for case management nurses to track infants in real time and reach out to hospitals, primary care providers, families, and specialists (including audiologists) for screening results. The Neometrics system is also used to track all hearing referrals made to partners, including TEIS, CSS, and Family Voices. Medical providers and audiologists are able to view and print newborn screening results via the Secure Remote Viewer (SRV) accessible from the Tennessee Department of Health Newborn Screening program website.

During the next project period, the current diagnostic follow up and early intervention referral data collected on the Audiology Reporting Form will be collected electronically using RDx (Remote Diagnostic Testing) to improve the timeliness of reporting results to the TN EHDI program. The module for electronic reporting is currently being developed and is planned to launch during year 1 of the upcoming project period. Once launched, the diagnostic results will be reviewed by newborn screening follow up staff and prompt referrals to early intervention, family support, and children's special services (CYSHCN). Early intervention enrollment data are received electronically into the Newborn Screening Health secure email from early intervention services. Early intervention enrollment data are then entered into the NDS by newborn screening follow-up staff. Statewide trainings for audiologists will be provided by the audiology consultant and the NBS nurse educator as soon as user acceptance testing is complete with RDx and the system for reporting is complete.

Ongoing trainings for audiologists, primary care physicians and new NBS case management staff will be provided by the audiology consultant to ensure JCIH, and American Speech and Hearing Association (ASHA) recommendations are being followed. An emphasis of education with medical homes providers will occur during year 1 which will include developing an infographic regarding the importance of diagnostic testing after newborns are initially referred.

Tennessee will continue to support tele audiology services with the Title V Children and Youth with Special Health Care Needs (CYCSN) program / Children's Special Services (CSS) by using funds as reimbursement to providers who utilize tele audiology services for follow up appointments which include cochlear implants and/or hearing amplification devices. These services, entitled "Listen Up" will be offered by a team of audiologists and speech pathologists who specialize in services to infants and young children who utilize a wide variety of amplification options including hearing aids, cochlear implants, other implantable devices, and assistance listening devices. Interpreting services will be available for all appointments, per family request. These services do not replace direct services provided by the child's pediatric audiologist, speech-language pathologist, or early interventionist, but will act as an additional layer of support to families during the early part of a child's journey as a new listener. A RedCap survey will be used to continue recording each appointment completed. The survey will ask questions which include demographics, hearing device used, and, if any, the number of hours the child wore the listening device. This service will continue throughout the next project period.

### **C. Lead family engagement and early childhood coordination:**

The Tennessee EHDI program takes pride in the relationships built with parents and families of children with hearing loss. There has been a long standing formal contractual relationship with the Tennessee Disability Coalition for family support. The Tennessee Disability Coalition houses Tennessee's Family Voices (FVTN) program along with our state Family-to-Family Health Information Center. For the next four year grant cycle, work will continue to be contracted with the Tennessee Disability Coalition to provide evidence-based in-home parent support for families of children with hearing loss. TN EHDI is continuously striving to improve family relationships and to actively engage parents in developing the program to best serve the citizens of Tennessee. Our staff and stakeholders understand that the EHDI program exists for the sole

purpose of helping each child born in Tennessee to have the opportunity to the best start in life regardless of hearing loss diagnosis or communication method. The Tennessee EHDI program and Tennessee Disability Coalition work collaboratively to adjust our goals and practices based on what families tell us they want and need, and to meet the changing environment and conditions in our state. As an example, Family Voices PEARS piloted having a part-time parent support specialist housed within the LeBonheur audiology clinic (located in Memphis – an area in our state with higher lost-to-follow up rates). The LeBonheur parent support specialist had dedicated space in the audiology clinic two to three days a week and met face to face with families at the time of hearing loss diagnosis to introduce family support resources. There are six parent guides that are located across to state to provide family support once a diagnosis is made and a referral is received from central office. Family Voices PEARS provided trainings to TEIS staff so that continuity of care for families would occur. Over the next project period, the pilot project will expand to include three parent guides (all parents of children with hearing loss) in three diagnostic audiology clinics located in large metropolitan areas of the state. More recently, the Family Voices Director has named a parent guide dedicated to work with all the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) trainees and to serve as faculty support to parent staff members that are participating in the LEND training program. LEND programs are HRSA/MCHB funded and provide long-term, graduate level interdisciplinary training, services, and care to improve the health of infants, children, and adolescents with disabilities. LEND accomplishes this by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by ensuring high levels of interdisciplinary clinical competence. Vanderbilt University's LEND program made a commitment a number of years ago to include a Family Voices PEARS trainee (a family staff member who is not necessarily enrolled at the university) and a Family Voices faculty member as participants in their LEND program. This was seen as an innovative practice that would enhance cultural competency, family-centered care, and interdisciplinary partnerships, as well as give all trainees a "real-life" perspective on families. Family Voices PEARS is represented in the advisory committee, regional task force meetings, and monthly conference calls with all contracted agencies. The close relationship accounts for numerous day to day phone calls with parent guides to ensure that statewide decisions are being made using a parent perspective. Working together, the family-based organization and the Newborn Hearing Screening program have developed a peer-based resource and support system for families of children who are deaf and hard of hearing.

Adults who are deaf and/or hard of hearing (DHH) are represented in regional task force meetings, the statewide advisory committee, and within the Family Voices PEARS program, acting as a support for families of children with hearing loss. The NBS program has long served as a member on the Tennessee Council for the Deaf, Deaf-Blind and Hard of Hearing. These meetings occur quarterly and integrate TN EHDI with adult support service providers, deaf community workshops, and current issues pertaining to adults who are DHH.

**D. Facilitate improved coordination of care and services for families and children who are DHH:**

The Tennessee Department of Health Newborn Screening Program revamped our hearing follow-up process in 2016 in order to refer 100% of infants with confirmed hearing loss to Tennessee's Early Intervention System (TEIS). Early identification of, and intervention with, children with hearing loss increases the likelihood for success in school and life regardless of socio-economic status, communication methods, and/or gender. Our program has recognized since 1999 that early intervention is an integral part of the hearing screening journey, and our formal partnership with TEIS began in 2001 to further support infants with hearing loss. Any Tennessee infant or child with hearing loss is eligible for TEIS services, including those with unilateral and/or unspecified hearing loss. Though our program now refers 100% of infants and children with hearing loss, not every child will complete enrollment in TEIS. Collecting hearing loss enrollment rates is also complicated by the fact that TEIS uses multiple diagnosis codes for enrollment which do not include fluctuating conductive hearing loss, so any child with concurrent diagnoses where hearing loss is secondary will not be captured in TEIS enrollment data for hearing loss.

Since 2017, the Newborn Hearing Program has worked closely with the Part C Early Intervention program, housed within the Tennessee Department of Education, to collect enrollment dates of children referred to the early intervention program (TEIS). Recognizing both HIPAA and FERPA regulations, an informal data sharing procedure was established in 2018 which embedded an authorization to release information (ATRI) form to be included in early intervention enrollment procedures. Once the form is voluntarily signed by families, the Part C Data Coordinator provides TN EHDI the individualized enrollment date. If the ATRI was not signed, TEIS provides child's age group at the time of enrollment, i.e. <6 months, 6-12 months and >12 months. A formal data sharing agreement between the Tennessee Department of Health and the Tennessee Department of Education Early Intervention System is in process, and work will continue through year 1 of the project. Once it is completed, the TEIS can share the enrollment date information with TN EHDI without the need of an individual ATRI form. Ongoing collaboration will be required during year 1 to ensure that both programs receive technical assistance and appropriate considerations to fulfill state and federal guidelines.

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**TEIS – TDOH Information and Data Sharing Process**  
Early Hearing Detection and Intervention (EhDI), Tennessee Department of Health (TDOH)

**Background:**

- EhDI legislation requires a shared partnership with IDEA Part C (TEIS)
- TDOH reports annually to the Center for Disease Control (CDC) on required federal indicators related to state hearing loss data. These data are reported nationally for every state.
- U.S. National EhDI Goals:
  1. Screening for hearing loss before one month of age
  2. Identify hearing loss before three months of age
  3. Enroll in early intervention before six months of age
- Referrals to TEIS
  - All referrals from the Department of Health or from an audiologist are for children who have a diagnosed hearing loss – 100% goal
  - These children are eligible for TEIS
- Data sharing from TEIS to TDOH
  - TEIS data addresses EHD national goal #3 (i.e., child with a diagnosed hearing loss is enrolled in early intervention (TEIS) before six months of age)
  - TEIS data shared is the child's DOB/AGE. This informs TDOH the date in which the child was enrolled in early intervention services.
  - Authorization for Release or Use of Information form with parent signature/date is REQUIRED to release information to TDOH for newborn hearing screening before TEIS can share data with TDOH.

**Please note:** the Acknowledgement of Referral CANNOT be used to share TEIS data.

**TEIS POI process:**

1. Process hearing loss referral received. Note: some referrals will be sent to the central office instead of the TEIS POI. These will be forwarded to the appropriate TEIS office.
2. At the next TCH or IEP meeting obtain parent signature/date on an Authorization for Release or Use of Information form to release information to TDOH for newborn hearing.
3. Provide Catherine Goodwin with verification that there is an Authorization for Release or Use of Information form to release information to TDOH. This can be done by any of the following ways listed below:
  1. Scan/send form to Catherine at [cath@gwin.goodwin@tn.gov](mailto:cath@gwin.goodwin@tn.gov)
  2. Fax form to Catherine at (615) 532-5942
  3. Email Catherine, informing her there is a signed Authorization for Release or Use of Information form in the child's record. Provide the following information in the email:
    - a. Child's name
    - b. Date of birth
    - c. Date of parent signature on the form
4. Notify Catherine should a parent decline to sign an Authorization for Release or Use of Information. Provide the following information:
  - a. Child's name
  - b. Date of birth
  - c. Date parent declined consent

April 28, 2018

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In addition, the Tennessee Department of Education, which houses TEIS, gifted the Newborn Hearing Program 30 OAE screening units that previously had been used in the field by TEIS service coordinators. These OAE units will continue to be distributed to midwives and providers that service the home birth community to increase the rate and timeliness of initial hearing screens among the home birth population. The Newborn Hearing Program will explore additional options for any unused units with local health departments in rural areas of the state where families have limited access to follow-up testing. This is another example of how the Newborn Hearing Program and TEIS work together to accomplish shared goals in order to better serve infants, children, and families.

As part of the upcoming project cycle, Family Voices PEARS (Parents Empowerment Access Resources Support) will continue to provide family support services to families of children recently identified with hearing loss. Historically, Family Voices PEARS has reported to TN EHDI: 1.) Number of individual parent guides; 2.) Number of parent support services for hearing loss; 3.) Number of outreach events; 4.) Number of people who attended the outreach events on a quarterly basis. During the first year, TN EHDI will collaborate with Family Voices PEARS to define what should be considered “number of families enrolled” and subsequently collect and report the number of families enrolled in services. Years 2 – 4 will measure number of families enrolled using Year 1 as the baseline data to report progress towards increasing families enrolled in family support services by 20% no later than six (6) months of age.

Year one (1) will be comprised of developing an internal procedure to link enrolled families with additional services, including the Parent 2 Parent program which is housed within the Tennessee Disability Coalition. The Parent 2 Parent program is an evidence-based service that utilizes a group of adults who volunteer to serve as mentors for families that request services. Volunteers have a range of diagnosis including deafness or experiencing hearing loss for themselves or a family member. Once an internal procedure has been developed, Family Voices PEARS will provide education regarding the program and offer the services to families, providing a referral when requested. Because families of children with hearing loss are referred immediately to

family support at diagnosis, the parent guide will work directly with the family to ensure referrals for services are based on informed parent decisions while embracing the cultural sensitivity of the unique family being served. Baseline data will be collected during year 1 to identify the number of families enrolled in DHH adult-to-family support services by no later than nine (9) months of age as baseline data for the remaining project period.

The General Assembly of the State of Tennessee passed legislation in 2019 which funded a two-year deaf mentor pilot project within the Tennessee Department of Education to assist families and agencies in implementing home-based programming for children who are deaf, hearing-impaired, or deaf-blind. The project will focus on preventing language deprivation; providing a positive impact on the child's social and emotional development through a deaf role model; and ensuring that children who are deaf have equal access to learning opportunities at home and in the community. The project will utilize a deaf mentor curriculum and must provide hearing parents of children who are deaf, hard of hearing, or deaf-blind with the option of using a deaf mentor to expose the parents' children to American Sign Language and deaf culture. The pilot project period will begin with the 2019-2020 school year. The Tennessee Department of Education will evaluate the pilot project to determine whether the project shall be continued or replicated. The Tennessee School for the Deaf staff responsible for this project attends TN EHDI regional task force meetings across the state and will provide further updates on the success of this pilot project.

In 2017, the first Care Project family retreat was launched in Tennessee funded through a combination of grants from public and private contributions. This opportunity promoted a full range of support for families of children recently identified with hearing loss which included child care and direct access to culturally competent education in order to make informed parent choices about their child's health care needs. During the next project period, the Care Project will work with both FVTN and the Newborn Hearing Program to expand support for families by hosting family retreats during years 1 and 3 of the funding period. This retreat will provide education including audiology, early intervention services, and resources. Additionally, parents will be able to connect with Family Voices PEARS parent guides and receive emotional support along with other families. The retreat will bring together multiple families that have a child that has hearing loss to allow networking, bonding and sharing of life experiences, and promotion of advocacy skills. The retreat will be a 2.5 day experience with a target of servicing 12-15 families.

In addition, TN EHDI will host two parent/professional collaborative conferences during years 2 and 4 of the grant cycle which will provide education for parents of children with hearing loss and promote empathy and a family perspective to professionals who provide services for children who have hearing loss. The conferences will be facilitated in a child-free environment, and parents will receive the following classes: Emotional Journey, Parent Leadership Training, Parents as Collaborative Leaders, Audiology (including tele-audiology), Communication Options, Literacy, and Technology; sessions for professionals will focus on: Sensitivity Training, Counseling Strategies, and Starting Parent Support Groups. TN EHDI and FVTN will work with the Care Project in the planning and promotion of the event, fostering leadership skills in parent guides throughout development, implementation, and evaluation of the program.

These family-centered and family-driven collaborations expand capacity to reach families and provide them with the unbiased supports and services they need to achieve their desired outcomes for their children.

Knowledge on key aspects of the EHDI program is crucial to early identification and early intervention with babies which leads to important decisions regarding the development of communication with a baby, nurturing language development, and supporting opportunities for the whole family. Health professionals and services providers will receive trainings from the Newborn Hearing Program throughout the project period in a variety of media outlets including a statewide learning community, regional task force meetings (teleconference and/or face to face meetings), advisory committee, trainings/webinars from FL3 and the National Technical Resource Center, and access to information on the tn.gov website. The newborn hearing program will work collaboratively with the contracted audiology consultant to gather information from providers regarding additional hearing loss topics of interest.

**E. Additional Expectations:**

National EHDI Conferences: EHDI staff including the program director and epidemiologist will attend the annual EHDI meeting throughout the project period.

Grantees Calls/Partner Agencies Calls: EHDI staff will attend all federal grantee calls, and calls with other national partners and with National Center for Hearing Assessment and Management.

FL3: TN EHDI staff will participate via conference call or refer the contracted family based organization to FL3 (national family based organization) trainings, and additional resources as provided.

Provider training: EHDI Staff will conduct outreach and education to health professionals and service providers in the EHDI system to reinforce the need for hearing screening up to age 3 to identify, diagnose, and enroll into EI those infants who pass a newborn screen but later develop hearing loss.

Coordination with LEND: Family Voices of Tennessee PEARS, TN EHDI's family support organization, will continue to work with Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program on behalf of the TN EHDI program.

In order to foster ongoing and sustainable improvement to the program, new strategies will be implemented in pilot or testing phases and evaluated for efficacy. Successful strategies (new or existing) will then be promoted as best practices and integrated into the program statewide and evaluated on an ongoing basis.

**WORK PLAN AND LOGIC MODEL**

**(See Attachment 1 – Work Plan with Evaluation Plan and Logic Model)**

**RESOLUTION OF CHALLENGES**

The Tennessee Newborn Hearing Screening program has a long history of passionate, active, and supportive stakeholders. Our strong network of stakeholders helps the program to evolve and improve to better meet the needs of infants and families in Tennessee. Stakeholders also help

identify and respond to challenges when they arise. The team of contractors and partnerships that the program has developed over the years strengthens the system in Tennessee not only for screening, identifying, and supporting children and families, but also for creative problem solving and addressing challenges.

The Tennessee American Academy of Pediatrics (TNAAP) Chapter Champion will also be a resourceful liaison to the physician community, and will offer an inroad in the collaborative process towards developing, implementing, and tracking shared goals.

The addition of the diagnostic module, named RDx is planned to launch during year 1 of the project period which will allow audiologists to enter diagnostic results online. A delay could occur based on previous experiences enhancing the newborn screening internet-based system (iCMS). Ongoing communication with Neometrics will occur throughout the project period to minimize any delay.

Local and regional WIC staff will need to discuss rescreening with parents and parents will need to schedule a rescreening appointment. This requires additional time from both staff and parents including referral procedures and access to resources. TN EHDI will provide a statewide audiology directory to WIC staff for existing regional resources to provide to families. Both the newborn hearing follow up program and WIC program are centrally located within the division of family health and wellness and have a strong existing relationship to problem solve additional challenges as they arise throughout the project period. Family Voices PEARS will additionally create a letter to distribute at WIC clinics to motivate parents to follow up with rescreening appointments. TN EHDI will explore the feasibility of WIC clinics assisting parents making appointments on-site before leaving the clinic.

The established data sharing procedure between TN EHDI and Part C early intervention services requires families to sign an authorization to release information before early intervention shares enrollment data. This requires additional time and burden on early intervention staff. A data sharing agreement is currently in process between both departments to remove the requirement of the individual family consent to share data with the TN Department of Health.

Family Voices PEARS receives referrals directly from the TN Department of Health once a child has been identified with hearing loss. Because family support services cannot be initiated until a diagnosis has been received, a parent guide will be present in three (3) diagnostic hospitals across the state to encourage families to follow up for further testing and provide immediate emotional support, as needed.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

- A. Program performance evaluation is integral part of the program. All program activities are planned so that they contribute to the achievement of the specific program objectives, though some activities may impact multiple objectives. One or more indicators are identified for each project action step in order to monitor its progress.
- B. As laid out in the work plan, six (6) objectives were listed, per recommendations in grant guidance document. Each objective is S.M.A.R.T. The hearing screening, diagnostic, and enrollment data are entered into the Tennessee's newborn screening data system. The data are analyzed and reported quarterly. Progress reports are received quarterly from contracted

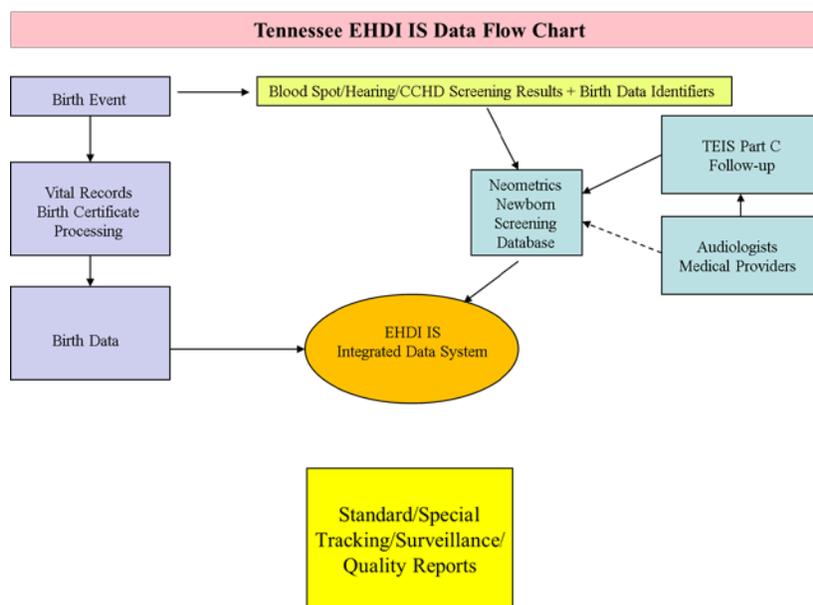
agencies and analyzed and included on annual progress reports. Combined data sets will serve as the data sources for monitoring the progress of the project objectives and/or as the baseline data for goal setting for the objectives #5 and #6.

- C. Since September 2014 the Tennessee Newborn Screening Program has a dedicated PhD level epidemiologist. She has access to both birth certificate data and the newborn screening data and links them on a weekly basis. Through this process the program is able to evaluate whether or not an infant born in Tennessee has received all screening components (hearing, metabolic, and critical congenital heart disease/CCHD). Based on the linked data, the program staff produces both summary reports and individual birthing facility reports to assess the completeness and timeliness of newborn screening and data quality. Reports have been developed to validate accuracy of data as the child progresses through the three components of hearing screening, diagnosis, and intervention to meet the 1 month, 3 month, and 6 month timeline for follow-up. Evaluation and tracking reports are developed using the Neometrics Crystal reports and Statistical Analysis Software (SAS). Data has been utilized to guide program activities to reduce loss to follow-up/loss to reporting/documentation after a failed screen, to track pending diagnostic evaluations by audiologists, to track follow-up reporting by primary care providers, and to target specific populations for quality improvement activities. This data is the main source for outcome measures needed for program evaluation. The data sources for process measures mostly come from the program records from the TN EHDI program director, contracted family support organization and the audiology consultant. The program staff will meet quarterly to review progress on both process and outcome measures and identify gaps which need to be addressed.
- D. The lead staff for the evaluation activities is Yinmei Li, MD, PhD. Dr. Li was the program evaluation director for CDC EHDI funded Tennessee EHDI-Tracking, Surveillance and Integration project from 2008 - 2012 and the project coordinator for the CDC EHDI-Information System project from 2013 - 2014. She has been supporting the HRSA funded Tennessee EHDI program since 2008. In Sept 2014 she joined the Newborn Screening Program and has since dedicated all her efforts to the program. She frequently presents Tennessee experiences at the national EHDI meetings, including “The Tennessee EHDI Information System” at the 13th Annual EHDI Conference in 2014, “EHDI in Tennessee: Developing collaborative partnerships over time” at the 14th Annual EHDI Conference in 2015, and “Factors Associated with Loss to Follow-up Among Infants Failing Initial Hearing Screenings” at the 18th Annual EHDI Conference in 2019. She recently submitted another abstract for the 2020 EHDI meeting titled “Loan and Train – A Novel Approach to Improving Hearing Screening among Tennessee Infants Delivered by Midwives”.
- E. TN EHDI data are part of the newborn screening data system on an Oracle server supported by Neometrics application, commercial software by the Natus Group. The initial hearing screening information is recorded on the filter paper form for the dried blood spot (DBS) specimens if hearing screening results are available at the time the DBS filter paper is mailed to the state newborn screening laboratory. If the hearing screen is conducted after the DBS is sent, the results are reported on another form, named Hear Only Form, and faxed or mailed to the newborn follow-up program to be keyed in by staff. Primary care providers also use the Hear Only Form to report screening results. The follow-up diagnostic results are faxed or e-mailed to the newborn screening program. The early intervention enrollment information is e-mailed to the newborn screening follow-up program. Both diagnostic and enrollment data are entered by the newborn screening follow-up staff. Once the RDx module is available the

audiologists can enter the diagnostic results into the newborn screening data system directly. Performance indicators on screening, follow-up and early intervention can be derived from the data captured in the newborn screening data system. Process measure data are recorded by the contracted agencies and reported to the TH EHDI quarterly.

In addition to be used for program evaluation, the newborn hearing screening data have been used to track all infants from birth through screening, diagnosis, and intervention. The system includes the key elements such as age at screening, age at diagnosis, and age at early intervention for monitoring the progress for meeting JCIH 1-3-6 goals. The data have also been used to guide various quality improvement activities. Following are three types of data reports generated regularly:

- i. Hospital specific reports:* Since September 2014, the program has been sending hospitals monthly summary reports on key performance indicators including the hearing screening rate for their own facility. Quality improvement staff also sends each hospital a report that lists all infants born in their facility that have not had a hearing screening and requests that the hearing screening results or refusal information be sent back to the newborn screening office via secure e-mail or fax.
- ii. Statewide reports:* Since March 2015, the program also has produced statewide monthly summary reports with similar information by birthing facility and places them on the program website (<https://www.tn.gov/health/health-program-areas/newborn-screening/newborn-screening/newborn-genetic-screening/reports-and-publications.html>) on the Internet for the public to access. The reports are updated on a monthly basis.
- iii. Data quality reports:* In addition, staff generates weekly reports that contain individual records that have conflicting or missing hearing information, e.g., hearing screening method and results do not match, missing hearing test date, inconsistent information on type and degree of hearing loss, etc. These reports are placed on a secured network drive and the newborn screening QI nurse checks those records on a weekly basis, contacts facilities, requests updated results, and makes corrections as necessary.



**Description of the TN EHDI data system:**

**Vital records data:** We have direct access to the Birth Statistical System (BSS) provisional file that is updated weekly. Averages of 2,000 new birth records are added into BSS with about 2-4 weeks of delay from date of birth. The BSS is collected by the Office of Vital Records which is also located in the Department of Health.

**Newborn screening data:** Newborn screening data are captured in the Neometrics Data System (NDS). We have real time, direct access to NDS. On average, about 2,000 new records are added into the system per week. The screening data are collected on the Dried Blood Spot form that includes information for hearing screening, and entered into the NDS by staff at the state laboratory.

**Data linkage:** Birth and newborn screening records are linked using deterministic matching. The matching is based on such information as newborn screening specimen control number, the infant's medical record number, mother's SSN, the infant's date of birth, and child or mother's name. The accuracy of linkage is based on above fields as well as additional data fields including birthing hospital, birth time and birth order, infant's sex, mother's resident address, and mother's resident zip code using a weighted method.

- F. Potential obstacles/challenges: The program does not foresee significant challenges for implementing the performance evaluation at this time. The TN EHDI project coordinator and team will monitor the progress of the evaluation quarterly and address issues identified accordingly.

**ORGANIZATIONAL INFORMATION**

**(See Attachment 5 – Project Organizational Chart)**

The Tennessee Department of Health's mission is to protect, promote, and improve the health and prosperity of people in Tennessee. The Tennessee Department of Health Early Hearing Detection and Intervention (EHDI) program, known as the Newborn Hearing Screening Program (NHS), is a population based service supported by the Title V Maternal and Child Health (MCH) Block Grant and the HRSA Early Hearing Detection and Intervention Program Grant. It is located in the Tennessee Department of Health (TDH), Division of Family Health and Wellness (FHW), within the Pediatric Case Management Follow-up Program.

FHW Central Office staff provides programmatic guidance and technical assistance to MCH programs. Direct services are generally carried out at the local level through health departments in all 95 counties and/or contracted agencies. Title V MCH Block Grant supported programs offered through the county health departments include women's health and family planning, services for children with special health care needs, and care coordination programs.

The Tennessee Department of Health, Early Hearing Detection and Intervention (Newborn Hearing Screening) Program oversees and continually strives to improve upon the statewide system to assure that all infants born in Tennessee receive a newborn hearing screening by 1 month of age, that those who do not pass the initial screen complete an additional hearing screen and/or diagnostic audiological evaluation by 3 months of age, and that those with identified

hearing loss are enrolled in early intervention and family support services by 6 months of age. The program automatically refers all infants and children identified with hearing loss to the Tennessee Department of Education, Early Intervention System (TEIS) – Part C program for service coordination, to Children’s Special Services for assessment for hearing aid financial and care coordination support, to the Tennessee Disability Coalition/Family Voices program for family support, and to the contracted audiologist, as needed, for follow up. The Newborn Screening Program conducts all hearing follow-up and refers infants identified with confirmed hearing loss to statewide referral partners.

A Quality Improvement office was created within the Pediatric Case Management and Follow-Up Program for newborn screening, including blood spot, hearing, and critical congenital heart disease (CCHD) screening. The program is participating in the national Collaborative Improvement and Innovation Network (CoIIN) for improving *Timeliness in Newborn Screening* and in the Newborn Screening Technical Assistance and Evaluation Program (NewSTEPS). Quality improvement is continuously achieved through shared collaborative learning of evidence-based strategies for the improvement of timeliness in the newborn screening process in several areas (collection of dried blood spots, transport of specimens and information, and receipt of specimens in the State Laboratory). A number of the activities benefit timely EHDI reporting by hospitals. To reduce the transport time of specimens (including hearing results), a specimen courier service has been provided to hospitals since April 2015. Courier services have resulted in a significant increase in the percent of blood spot forms received by the lab less than 48 hours from collection. In 2014 the program began creating and providing monthly quality reports for each hospital and also made these available to the public on the Department’s website. The reports include the number of births and the percentage of blood spot, hearing, and CCHD screens completed. Also included are statistics on the number of unsatisfactory specimens, age at collection, and time in transit. A report of infants not screened (including for hearing) is also sent to the hospitals, and the hospitals are expected to complete and return information with dates of screen or the reason not screened. **(Attachment 8 – Newborn Screening Collection Form)**

The Tennessee Newborn Hearing Screening (EHDI) and HRSA Newborn Hearing Grant Program Director serves at 1.0 FTE which is provided in-kind and funded by the Title V Maternal and Child Health Block Grant. The current Program Director joined the Tennessee Department of Health, Pediatric Case Management and Follow-up Program in March 2019. The program director works closely with the seven full-time pediatric case management nurses, one quality assurance nurse, one nurse educator, and the epidemiologist in charge of the newborn hearing follow-up data program. The Newborn Hearing Screening program also benefits greatly from dedicated epidemiological support for pediatric case management (blood spot, hearing, lead, and CCHD) to develop data systems and reports to evaluate program services and improve upon quality improvement strategies. The Newborn Screening Program epidemiologist will be responsible for evaluating Newborn Hearing Program activities and will be funded by the Title V Maternal and Child Health Block Grant. **(Attachment 2 – Staffing Plan and Job Descriptions for Key Personnel)**

The Newborn Screening Program is housed within Pediatric Case Management Follow-Up in the Division of Family Health and Wellness. Seven nurse case managers conduct follow-up for

newborn hearing and metabolic screening, one nurse educator provides outreach education to hospitals, one quality assurance nurse has been assigned specifically for QI activities, and one nurse coordinator manages the section. All pediatric case management nurses are cross-trained in hearing, metabolic, and childhood lead poisoning prevention program follow-up procedures and rotate program duties on a monthly basis. An additional program director position was hired in 2017 (funded by the MCH Block Grant) to coordinate the genetics and perinatal contracts for the Newborn Screening Program. Newborn screening results are documented on the blood spot card in the hospital at time of collection (including hearing results) and delivered via courier to the State laboratory. Infant demographic information and newborn screening results are entered into the Neometrics data system which is utilized by the case management nurses for follow-up. Follow-up actions and requests for hearing results are generated on a timeline keeping with Joint Committee on Infant Hearing (JCIH) 1-3-6 goals.

The Newborn Hearing Screening program administers two sub-contracts to provide the state program with services by staff classifications that the Department of Health does not employ. Family support is provided via contract with the Tennessee Disability Coalition which houses Family Voices of Tennessee. Seven parent staff members provide home visits, calls, emails and other means of support to families of children who are newly diagnosed with hearing loss. Their goal is to give parent-to-parent support according to the family's individual terms and preferences. Parent staff members also conduct community outreach and training, host family networking activities to informally link families of children with hearing loss together, provide materials and consultation to promote non-biased selection of language and communication methods, and liaise with early intervention services. Each parent staff member is themselves a parent of a child or children with hearing loss, each with a unique story and journey through screening, diagnosis, intervention, and support. Certain parent staff members also serve as board members with the Tennessee Chapter of Hands and Voices in order to foster collaboration and link families to both local and statewide resources.

A new contract for a part-time audiology consultant (0.75 FTE) is currently in the bidding process, and the contract will be responsible for developing and conducting statewide training as requested by the program. The audiologist provides phone and onsite consultation and training to hospitals, audiologists, primary care providers, midwives, families, early intervention, Early Head Start, and other organizations. The agency/university selected will also support the program director by participating in the regional task force meetings as well as quality improvement projects, and will be responsible for training the audiologists across the state with the nurse educator regarding remote diagnostic reporting, RDx, in the next project cycle. Additional tasks will include individualized follow-up with nurse case managers regarding best practice recommendations for families of children with hearing loss. (**Attachment 3 – Biographical Sketches of Key Personnel & Attachment 9 – Descriptions of Existing Contracts**)

Tennessee Department of Health and Tennessee Department of Education continue to share data via a cross-reference follow up report that is provided from the Department of Health to the Department of Education, Tennessee Early Intervention Service (TEIS) Newborn Hearing Coordinator. This follow up report is a list of children who have *not* been recorded in iCMS database from the Department of Health as having an IFSP date (initiation of early intervention

services). The newborn hearing coordinator within the early intervention services central office reviewed the list provided, researched the Tennessee Early Intervention database system (TEIDS), and sent IFSP enrollment dates back to the program via secure electronic mail. In 2018 it was determined by the Department of Education that an authorization to release information (ATRI) form was required to be signed by parents in order to share IFSP enrollment dates with the Department of Health. A quarterly spreadsheet is prepared from the TDH program epidemiologist which is sent to the TEIS Newborn Hearing Coordinator with those babies who were referred. The TEIS Newborn Hearing Coordinator provides the following data: 1) ATRI signature status; 2) IFSP enrollment date, if ATRI signed; and 3) Enrollment status if ATRI not signed. The EHDI program coordinator continues to provide technical assistance to the early intervention services team to ensure children with hearing loss receive timely services. TDH and TEIS are currently working on a Memorandum of Understanding (MoU) in order share information more quickly.

Six regional EHDI task force meetings have been taking place in Tennessee since 2014. Regional task force members meet in person once a year, with regional follow-up conference calls, in an effort to utilize regional and multifaceted collaboration to reduce the percent of infants that are lost to follow-up/lost to documentation, to engage primary care providers in 1-3-6 goals, and to integrate families of children with hearing loss into statewide EHDI goals and objectives. In Year 1 of the next project period, the Middle Tennessee Learning Community will shift to a statewide Learning Community that will expand participation from a variety of additional stakeholders including additional family members of a child who is deaf or hard of hearing, and other stakeholders to engage in a shared learning process to facilitate adaptation and implementation of innovations to the Tennessee EHDI program. Depending on the success of the initial learning community we will reassess shifting the model of other regional task force meetings into the learning community model. Going forward, the small steps of change process will be further utilized; and effective plans will be replicated and disseminated.

Central Office newborn hearing program staff and activities which are supported by MCHB Title V Block Grant funds and other Newborn Hearing Screening Program funds, will continue to be funded. Partners and contract staff continue to seek financial support from additional private and public organizations and agencies to provide activities and materials, especially for families. The Tennessee EHDI program also benefits from unique partnerships with graduate audiology students from East Tennessee State University, University of Memphis, University of Tennessee Knoxville and Vanderbilt University. No-cost contracts are in place between the State of Tennessee Department of Health and these institutions for specially trained graduate audiology students at each university to provide follow-up and, if needed, care coordination for infants that either have no initial hearing screen results or have no re-screen results after referring on the initial screen. Two more universities, East Tennessee State University and University of Memphis, have no-cost contracts in place as of September 2016 and will train students to participate beginning January 2017. This remarkable collaboration between the Newborn Hearing Program and the aforementioned universities in Tennessee allows our program to expand our continuum of care and provide more comprehensive hearing follow-up, along with care coordination when needed, to help families throughout the entire state meet JCIH 1-3-6 goals and experience better outcomes for their children.

Additional partnerships include participation as board members/advisory committee members for the Tennessee Deaf-Blind Project, Tennessee Newborn Screening Genetics Advisory Committee, Tennessee Council for the Deaf Deaf-Blind and Hard of Hearing, and the Tennessee Early Intervention System (TEIS) Interagency Coordinating Council. Tennessee Disability Coalition/Family Voices parent staff participates as members and/or advisory roles in the Ear Foundation, Sertoma Club, Hands and Voices, Memphis Oral School, Mama Lere Hearing School, the six Deaf and Hard of Hearing Centers, and other community groups serving the Deaf and Hard of Hearing Community.

### **Sustainability**

The Tennessee Department of Health Newborn Hearing Screening Program has historically been supported by state and/or MCH Block Grant funds, in the years prior to federal grant assistance. All Department of Health staff positions necessary for the oversight and execution of the program are provided in-kind. This includes the program director, case management follow-up nurses, quality improvement nurses, nurse educator, administrative services staff, and the section physician/medical director. HRSA grant funds have, in past grant years, exclusively supported direct family engagement services through the Tennessee Disability Coalition contract, audiology consultant services, and travel to the national EDHI Conference. Were HRSA funds to become unavailable, key components of the program would most likely continue to be supported by the State of Tennessee Department of Health.