

2021 ANNUAL REPORT



The Diagnostic Dilemma

**Language and Literacy Outcomes for Children Who are Deaf
and Hard of Hearing in the State of Georgia**

Report to the Governor and General Assembly as required by OCGA 30-1-5 (h)

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Rationale for Report and Legislative Charge

On May 8, 2018, HB 844 was signed into law as Act 462 and amended Chapter 1 of Title 30 of the Official Code of Georgia Annotated (OCGA) by revising Code Section § 30-1-5. This legislation was sponsored by Representative Penny Houston and Senator P.K. Martin, both longtime advocates for Georgia's Deaf and Hard of Hearing (DHH) community. The revisions stipulate ten key deliverables listed below which aim to improve the language and literacy outcomes for Georgia's children who are DHH. One of the key deliverables required by this legislation is for the Georgia Commission for the Deaf or Hard of Hearing (GaCDHH) to deliver a report to the governor and General Assembly annually to measure progress towards age-appropriate language and literacy outcomes for children who are DHH:

A report detailing the provision of early intervention (EI) and school-age services and the language and literacy outcomes for children who are Deaf or Hard of Hearing between the ages of birth and eight years shall be completed on or before September 1, 2019, and a similar report shall be completed on or before September 1 every year thereafter. Such report shall be jointly authored by the Department of Public Health (DPH), the Department of Early Care and Learning (DECAL), and the Department of Education (GaDOE) and approved by the commission (GaCDHH) and the advisory committee. The commission shall make the report available to the public on its website and present this report to the governor and General Assembly no later than September 15, 2019, and every September 15 thereafter.

OCGA § 30-1-5 (h)



Below are the key deliverables and their status as stipulated by OCGA § 30-1-5.

OCGA 30-1-5 Deliverable	OCGA § 30-1-5 Reference	Status
1. Changes to the GaCDHH	(b)(1)(A)	Complete
2. Establishment of Multi-Agency Task force	(c)(1) through (4)	Complete
3. Establishment of Stakeholder Advisory Committee	(d)(1) through (3)	Complete
4. Georgia Testing Identifier (GTID) process and implementation	(g)(1) and (2)	From August 2018 to August 2021, 961 GTIDs have been assigned to infants identified with permanent hearing loss. Data Sharing Agreements among programs and state agencies are in development to ensure the assigned GTID number is included in transitions.
5. Web and print based parent/professional resource	(e)(2)	In Progress. A single source DHH website for parents and professionals is currently being created by the GaDOE's State Schools Division and the Georgia Technology Authority (GTA).
6. Create List of Developmental Milestones	(e)(1)	Language Developmental Milestones for Spoken Language (English) and American Sign Language (ASL) were created by the Stakeholder Advisory Committee. The Language Developmental Milestones documents are in the final editing phase and will be made publicly available on the website provided by OCGA § 30-1-5 (e)(2).
7. List and Implementation of Biannual Language and Literacy Assessments	(e)(3)	Biannual language assessments are currently given to all DHH children aged 0-3 years if enrolled in state-supported early intervention services (i.e., Babies Can't Wait [BCW] and Georgia PINES). The OCGA 30-1-5 Interagency Taskforce is working to create a data-sharing agreement so that birth to three language assessment data can be shared among state agencies such as DPH, GaDOE State Schools Division, and the Department of Early Care and Learning (DECAL) as well as Local Education Agencies (LEAs). Children in the school-age years (i.e., 3 years to 3rd grade) may currently receive biannual language assessments from the GaDOE State Schools Division for ASL only. Spoken English assessments will be targeted in the 2021-22 school year. Formative literacy assessments are currently given three times a year to all DHH students at the GaDOE's State Schools for the Deaf. Formative literacy assessment data collection for DHH students statewide (i.e., enrolled in LEAs) will be targeted in the 2022-23 school year. Summative statewide literacy assessments (i.e., Georgia Milestones, GMAS and Georgia Alternative Assessment, GAA) are currently given to all DHH students enrolled in public schools at the end of each school year. These data are collected, analyzed, and reported in the OCGA § 30-1-5 Annual report.
8. Development and Implementation of an Individualized Child Report (birth to literacy)	(e)(4)	Not Started
9. Interagency Collaboration, Provision of Seamless Services and Data Sharing from birth through high school graduation	(g)(1)	Ongoing - Key recommendation in this report is to convene multiagency task force to ensure collaboration
10. Annual Legislative Report	(h)	Complete

Executive Summary

The Problem

As stated in the OCGA § 30-1-5 Year 1 Report, Georgia’s children who are DHH have both the ability and the right to achieve every educational outcome that children with typical hearing can achieve. However, this achievement is dependent on equitable access to timely diagnosis and appropriate early intervention (EI) and school-age services.

Per OCGA § 31-1-30, all infants in Georgia must receive a Newborn Hearing Screening before discharge from the hospital. While 94% of Georgia infants who were born in 2020 were reported as screened for hearing loss by one month of age, only 22% of the infants identified as needing a full diagnostic hearing evaluation were reported to have received the evaluation by three months of age – down from 28% in 2017.¹ While 2020 data are preliminary, it is expected that the COVID-19 pandemic has exacerbated this diagnostic dilemma, and many more infants who may be DHH have not been diagnosed and are not receiving timely EI and family support services as a result. Without a diagnosis of hearing loss, children and families are ineligible for most private, federal, and state-supported early intervention services.

Far too many Georgia children who are DHH do not achieve age-appropriate language or on-grade-level reading proficiency largely due to a lack of access to timely and appropriate services. It is expected that the ongoing pandemic has understandably intensified these access issues. Children who do not receive timely diagnostic testing and EI and family support are unlikely to achieve age-appropriate language and struggle to achieve on-grade-level literacy skills. This has an economic impact on the state as literacy rates impact state expenditures (e.g., special education and social welfare costs) and income tax revenues (e.g., depressed employment rates) for this population. Our DHH children’s academic success starts with equitable, timely access to hearing screenings/evaluations and audiological care.

The Solution

This OCGA § 30-1-5 Year 3 Report outlines several programs and state agencies focused on the state’s diagnostic process. While serving the DHH population can be challenging given its low incidence, other contributing factors such as geographic location, socioeconomic barriers, and a lack of equitable access to public and private services continue to hinder outcomes for children who are DHH and their families. Research clearly shows that children who are DHH who have been identified in early infancy, enrolled in EI no later than six months of age, and who have received appropriate EI services will be on a path to later academic success in the school-age years.^{2 3} However, addressing disparities in access to quality care requires intentional action to improve data systems, increase regulatory vigilance, fund new initiatives that train health and education professionals in responsive care, and recruit providers, early interventionists, and school-age educators from diverse backgrounds.⁴ The goal of OCGA § 30-1-5 as amended by Act 462 (2018) is to create an individualized, *child-focused* ecosystem that supports a seamless provision of services for children and families as they move

¹ Georgia DPH 2016-2020 HSFS Data for PHIP Request as of 8-15-2021

² Moeller, M. P. (2000). Early Intervention and Language Development in Children Who Are Deaf and Hard of Hearing. *PEDIATRICS*, 106(3), e43.

³ Yoshinaga-Itano, C., Sedey, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of Early- and Later-identified Children With Hearing Loss. *Pediatrics*, 102(5), 1161–1171. <https://doi.org/10.1542/peds.102.5.1161>

⁴ Williams, Ph.D., M.P.H., D. R., & Rucker, Ph.D., T. D. (2000). Understanding and Addressing Racial Disparities in Health Care. *Health Care Finance Review*, 21(4). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194634/>

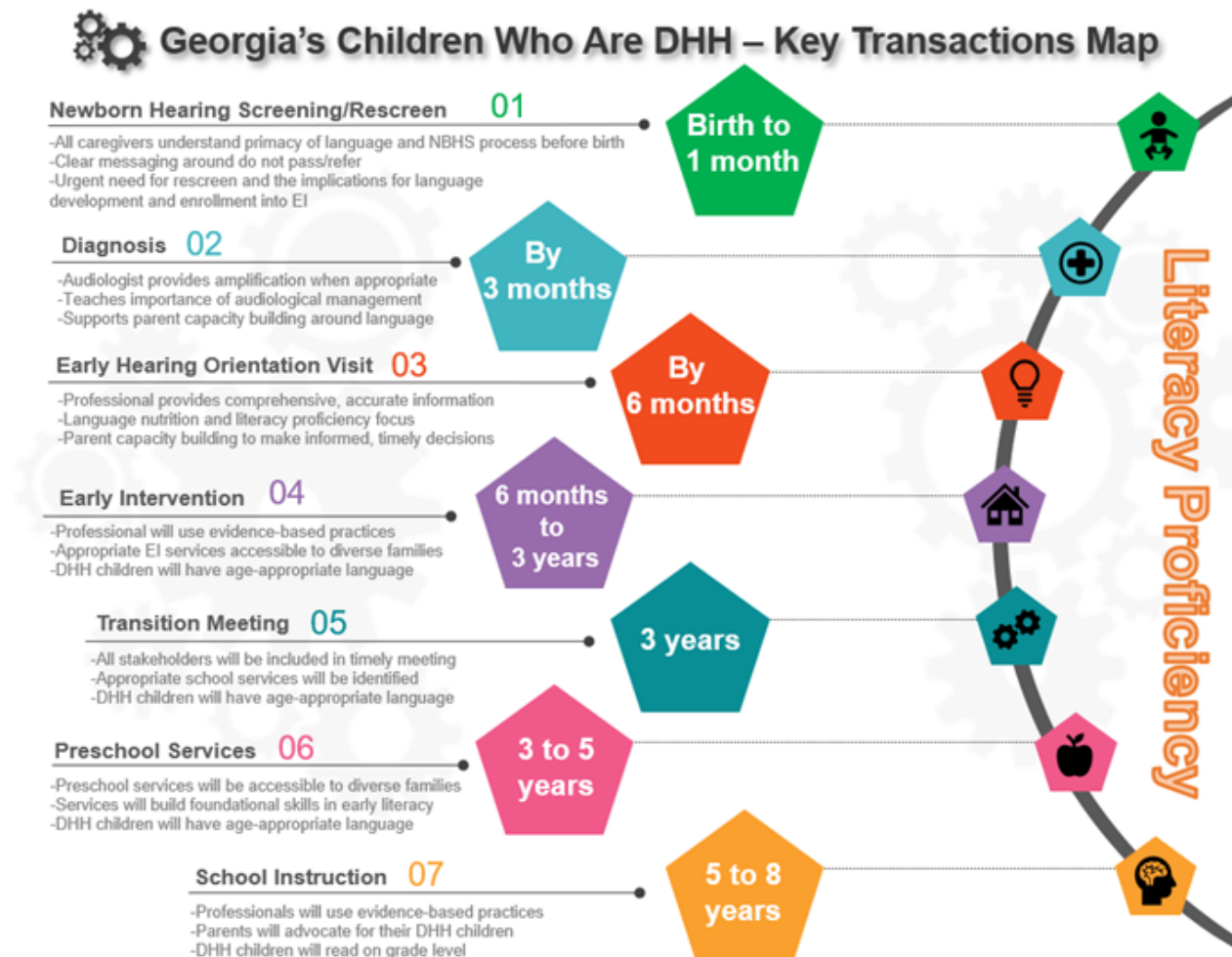


through the seven key transactions necessary for age appropriate language and literacy outcomes (as described below).

This report will outline several pieces of legislation for Governor Kemp and the General Assembly to consider as well as other efforts to address the low rate of diagnosis in Georgia. One potential effort addressing Georgia's Diagnostic Dilemma is the Georgia Department of Education's (GaDOE) State Schools Division grant submission to the Governor's Emergency Education Relief Funds initiative (GEER-II) entitled Collaborative Rapid Scaling of Statewide Tele/Mobile Audiology Capacity to Improve Diagnosis of Hearing Loss Among Infants Missed during COVID-19. If funded, this initiative will leverage existing Georgia programs with proven success in providing diagnostic testing to infants via mobile and/or teleaudiology services. These programs are committed to collaborating with the Georgia Department of Public Health's Early Hearing Detection and Intervention (EHDI) program to rapidly scale their diagnostic capabilities statewide to provide follow-up diagnostic testing to as many infants as possible.

Key Transactions for Children who are DHH

The transaction map below provides guidance for families on their journey from birth to literacy. Seven key transactions are identified based on best practices (as determined by the Joint Committee on Infant Hearing [JCIH], the Centers for Disease Control [CDC], the DPH, the DECAL, and the GaDOE) and are presented in chronological order along with a brief description of what should occur within each transaction as well as the critical period for completion.^{5 6 7} If the state ensures every child who is DHH can complete these transactions in a timely and coordinated manner, Georgia's Children who are DHH will be able to achieve proficient language and literacy skills in significantly greater numbers. This report aims to quantify the number of children who are DHH lost at each transaction point contingent on data availability.



⁵ Hugh W. C., Fey, M. E., & Proctor-Williams, K. (2000). The relationship between language and reading: Preliminary results from a longitudinal investigation. *Logopedics Phoniatrics Vocology*, 25(1), 3–11. <https://doi.org/10.1080/140154300750045858>

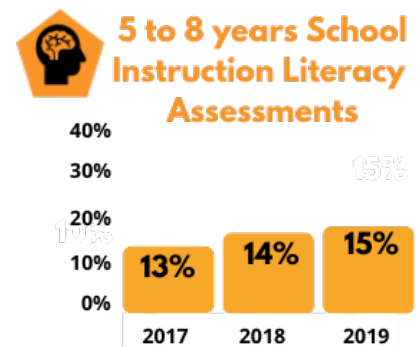
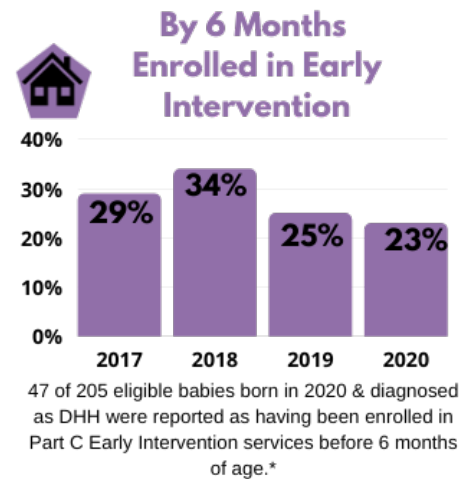
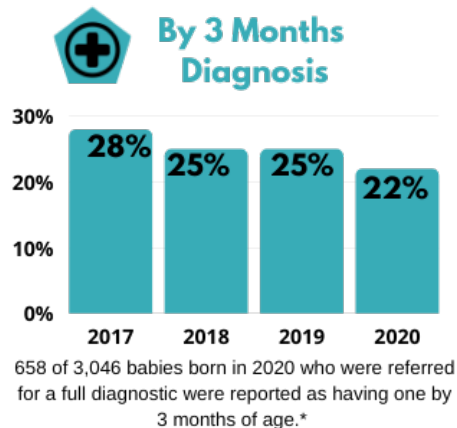
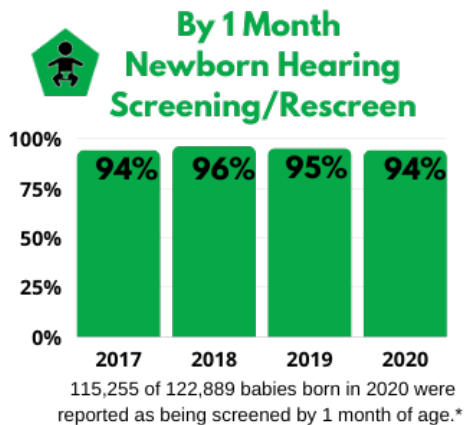
⁶ Easterbrooks, S. R., Lederberg, A. R., Miller, E. M., Bergeron, J. P., & McDonald Connor, C. (2008). Emergent Literacy Skills During Early Childhood in Children With Hearing Loss: Strengths and Weaknesses. *The Volta Review*, 108(2), 91–114. <https://doi.org/10.17955/tvr.108.2.608>

⁷ Dickinson, D. K., McCabe, A., & Essex, M. J. (2006). A window of opportunity we must open to all: The case for preschool with high-quality support for language and literacy. Guilford Press.

The 2021 DHH Language and Literacy Dashboard

In the 2019 Annual Report, the authors developed the DHH Language and Literacy Dashboard. This dashboard was designed to determine the current state of language and literacy outcomes and to measure progress towards age-appropriate language and on-grade-level literacy. The current dataset in this report includes data for 2017, 2018, 2019 and preliminary data from 2020 provided by the Georgia DPH and the Georgia Department of Education (GaDOE). The dashboard below represents Georgia's progress in each of the key transactions for which data were available.

2021 DHH Language and Literacy Dashboard



20 of 130 children in SPED with primary eligibility of DHH were reading on grade level by the end of 3rd grade for the 2018-19 school year.

*Sources: Georgia DPH 2016-2020 HSFS Data for PHIP Request as of 8-15-2021; GaDOE 2015-19 School Year End of Grade Assessments, Grade 3 Milestones English Language Arts Assessment for children in Special Education with a primary eligibility of DHH. Data unavailable for 2019-20 school year due to lack of testing during the COVID-19 pandemic.

Georgia's DHH Diagnosis Dilemma

Per Georgia law (OCGA § 31-1-30), all infants must receive a newborn hearing screening before being discharged from the birthing hospital or birthing facility. As a result, compliance with screening in the hospital is high. In 2020, preliminary data show that 94% of infants born in Georgia were reported as receiving their newborn hearing screening by one month of age which is on track to meet guidelines from the CDC. In accordance with CDC guidelines, all infants who fail their newborn hearing screening should receive a rescreen and/or full diagnostic evaluation by three months of age. Pre COVID-19, Georgia's on-time diagnostic numbers were behind most other states in the nation. Therefore, this report will focus on Georgia's "diagnostic dilemma" and will identify key barriers to obtaining a diagnostic evaluation.

Why Diagnosis of Hearing Loss is so Critical

When infants do not receive a timely diagnosis (i.e., by three months of age or earlier), it is almost impossible for parents and professionals to ensure that these infants receive the services needed to achieve age-appropriate language and on-grade-level literacy. Sadly, 68% of infants who do not receive a diagnosis or who receive a late diagnosis will present with *preventable* language delays and later academic delays as a result of the lack of early diagnosis and intervention.⁸

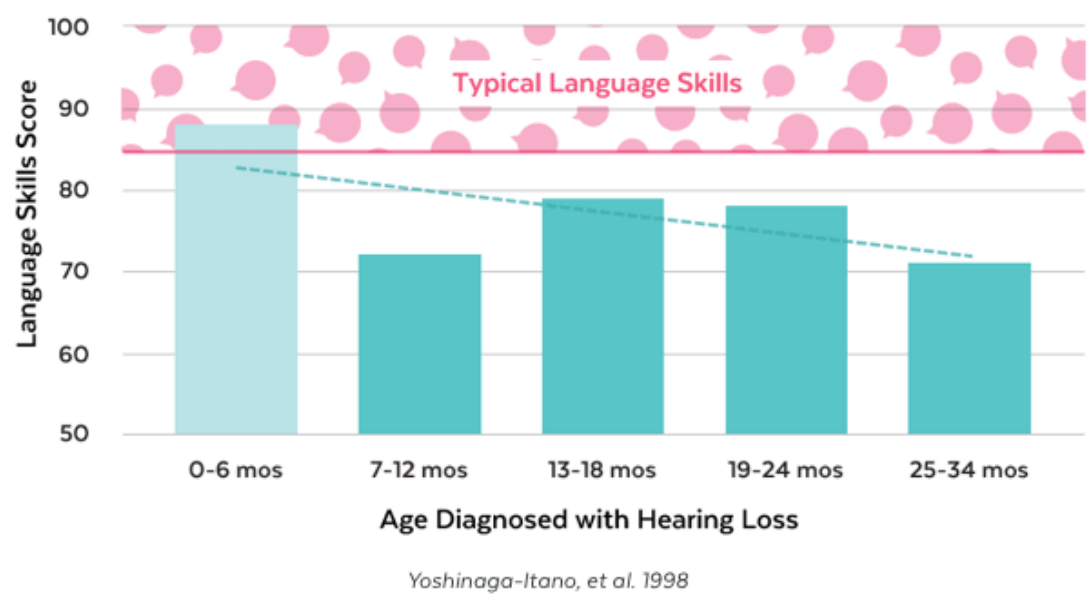
It does not have to be this way. As stated in the previous OCGA § 30-1-5 Language and Literacy reports, children who are DHH can realize social and academic outcomes equivalent to their typically hearing peers in the absence of secondary disabilities. Families may choose to support language and communication development in several ways. They may choose to pursue spoken language development with assistance from hearing technology such as hearing aids or cochlear implants, families may choose to support American Sign Language (ASL) development with support from the Deaf Community and the GaDOE's Georgia Parent-Infant Network for Educational Services (Georgia PINES) Deaf Mentor Program. Some families may choose a bilingual approach combining aspects of spoken language and ASL. No matter the language approach, the important factor to note is that children who are DHH can achieve outcomes commensurate to children with typical hearing, *but only if* they are diagnosed on time and receive appropriate EI and family support.

The graph below illustrates that children who are DHH who are diagnosed early can develop age-appropriate language skills by three years of age. However, the ability to achieve age-appropriate language drastically declines as the age of diagnosis increases. Bottom line, Georgia must provide equitable access to timely diagnostic evaluations to all Georgia infants who fail their newborn hearing screening if our children who are DHH are going to have a true chance at realizing their full language and literacy potential.

⁸ Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Journal of Early Hearing Detection and Intervention, 4(2), 1-44. DOI: 10.15142/fptk-b748

Given the longitudinal state-level data, equitable and timely access to diagnostic services has not and is not happening for the majority of DHH children. This is not to say that state’s role in helping children who are DHH stops at diagnosis. Access to timely, responsive EI services and evidence-based education services are essential to ensuring Georgia’s children who are DHH develop age-appropriate language and on-grade-level literacy. However, it is important to emphasize that without a DHH diagnosis, families are not eligible for DHH EI services. Therefore, Georgia’s diagnostic dilemma is the focus of this report.

Language Skills at Three Years of Age Depending on Age Diagnosed with Hearing Loss



Negative Economic Impact Due to the Lack of Timely Diagnosis

In addition to the direct impacts on child development, the lack of timely diagnosis has a financial impact on the state of Georgia. Consider the following:

- The lifetime educational costs for addressing hearing loss (more than 40 dB HL permanent loss without other disabilities) have been estimated at \$152,208 per child (adjusted for 2021).⁹
- During the 1999–2000 school year, the total cost in the U.S. for special education programs for DHH students was \$18,035 per child (adjusted for 2021).¹⁰
 - The GaDOE has identified approximately 2,600 DHH students who are in special education statewide PreK-12th grade. This equates to approximately \$47M per year in educational costs.¹⁰
- It is expected that the lifetime costs for all people with hearing loss who were born in 2000 will total \$2.1 billion (in 2003 dollars).¹⁰
 - Direct nonmedical expenses, such as home modifications and special education, will make up 30% of these costs.
 - Indirect costs, which include the value of lost wages when a person cannot work or is limited in the amount or type of work he or she can do, will make up 63% of the costs.
 - Note: These estimates do not include other expenses, such as hospital outpatient visits, sign language interpreters, and family out-of-pocket expenses. The actual economic costs of hearing loss, therefore, will be even higher than what is reported here.
 - Three other peer-reviewed research studies estimate the additional, incremental costs of educating a child who is DHH in special education is between \$10,587 and \$11,414 annually. [Grosse, S. D. (2018)].¹¹

Best practice guidelines promoted by the CDC, the Health Resources & Services Administration (HRSA), and the JCIH among others recommend the following guidelines for identifying infants who may be DHH:

- 1 = Infants should be screened for hearing loss no later than 1 month of age.
- 3 = If the baby does not pass a newborn hearing screening, they should receive a diagnostic hearing evaluation as soon as possible but no later than 3 months of age.
- 6 = If a baby is identified with hearing loss, they should be enrolled in EI by 6 months of age.

JCIH supports transitioning to EHDI 1-2-3 guidelines for states meeting the EHDI 1-3-6 guidelines, which Georgia has not accomplished yet. If infants are identified and receive EI via EHDI 1-3-6 guidelines, many costs can be reduced, as children who are DHH and who are meeting the benchmarks are less likely to need SPED services. If 100 infants receive timely diagnosis and appropriate EI services that result in age-appropriate language development and the eventual placement in general education, the average savings would be (\$11,000*100) or \$1,100,000 per year for this cohort.

⁹ Grosse SD. Education cost savings from early detection of hearing loss: New findings. *Volta Voices* 2007;14(6):38-40.

¹⁰ \$18,035 DHH special education annual cost x 2,600 GA DHH Special Education student population = \$46,891,000.

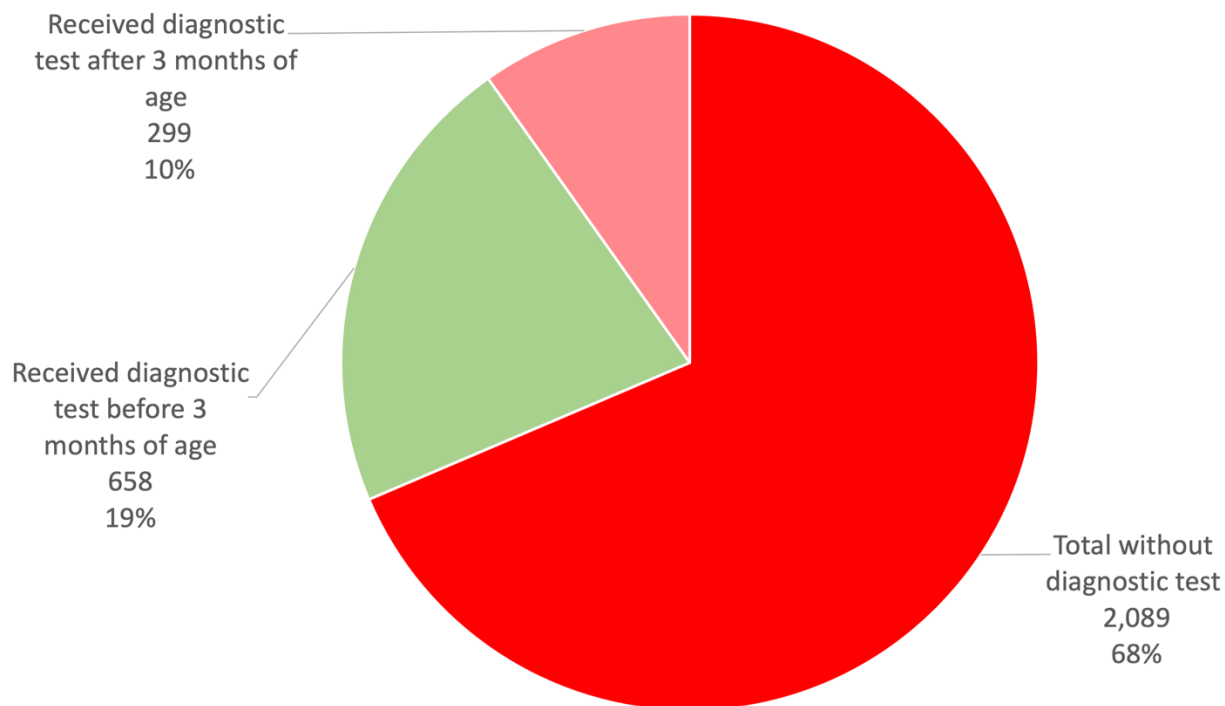
¹¹ Grosse, S., Mason, C., Gaffney, M., Thomson, V., & White, K. (2018). What Contribution Did Economic Evidence Make to the Adoption of Universal Newborn Hearing Screening Policies in the United States? *International Journal of Neonatal Screening*, 4(3), 25. <https://doi.org/10.3390/ijns4030025>

Lost Children - Children who are DHH Who are Not Reported with a Diagnostic Test

EHDI 1-3-6 data focus on the percentage of children reported as completing the first three transactions (i.e., newborn hearing screening, diagnostic evaluation, and enrollment into EI) by the recommended timeline. Children reported as not meeting a 1-3-6 benchmark transaction are referred to as “lost to follow-up”, and they are not calculated in the child cohorts for transactions following the missed/unreported transaction. For instance, EI enrollment is measured *as a percentage of the children Georgia enrolls in EI out of the number of children diagnosed as having hearing loss*. This calculation does not include the children lost to the DHH ecosystem altogether because they never made it to the second transaction (i.e., diagnostic evaluation) or results of the diagnostic hearing evaluation were not reported to EHDI. To resolve Georgia’s diagnostic dilemma, the state must focus on the children lost to the DHH ecosystem.

The chart below illustrates the scale of Georgia’s diagnostic dilemma. In 2020, almost 70% of the infants who failed their newborn hearing screenings are not reported as having received a follow-up diagnostic test to determine their hearing status.

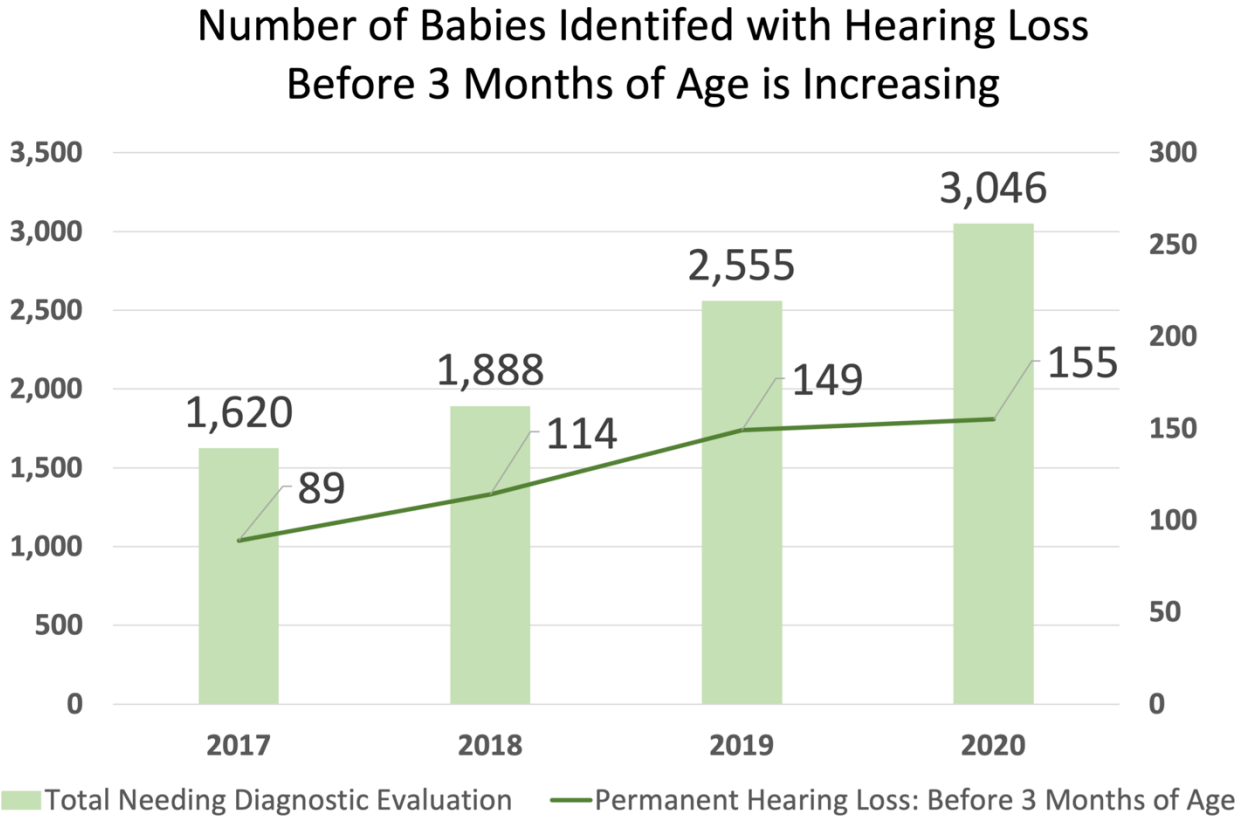
Over 2,000 babies born in 2020 who failed their newborn hearing screening are not reported as having received a follow up diagnostic test



Source: 2016-2020 HSFS Data for PHIP Request as of 8-15-2021

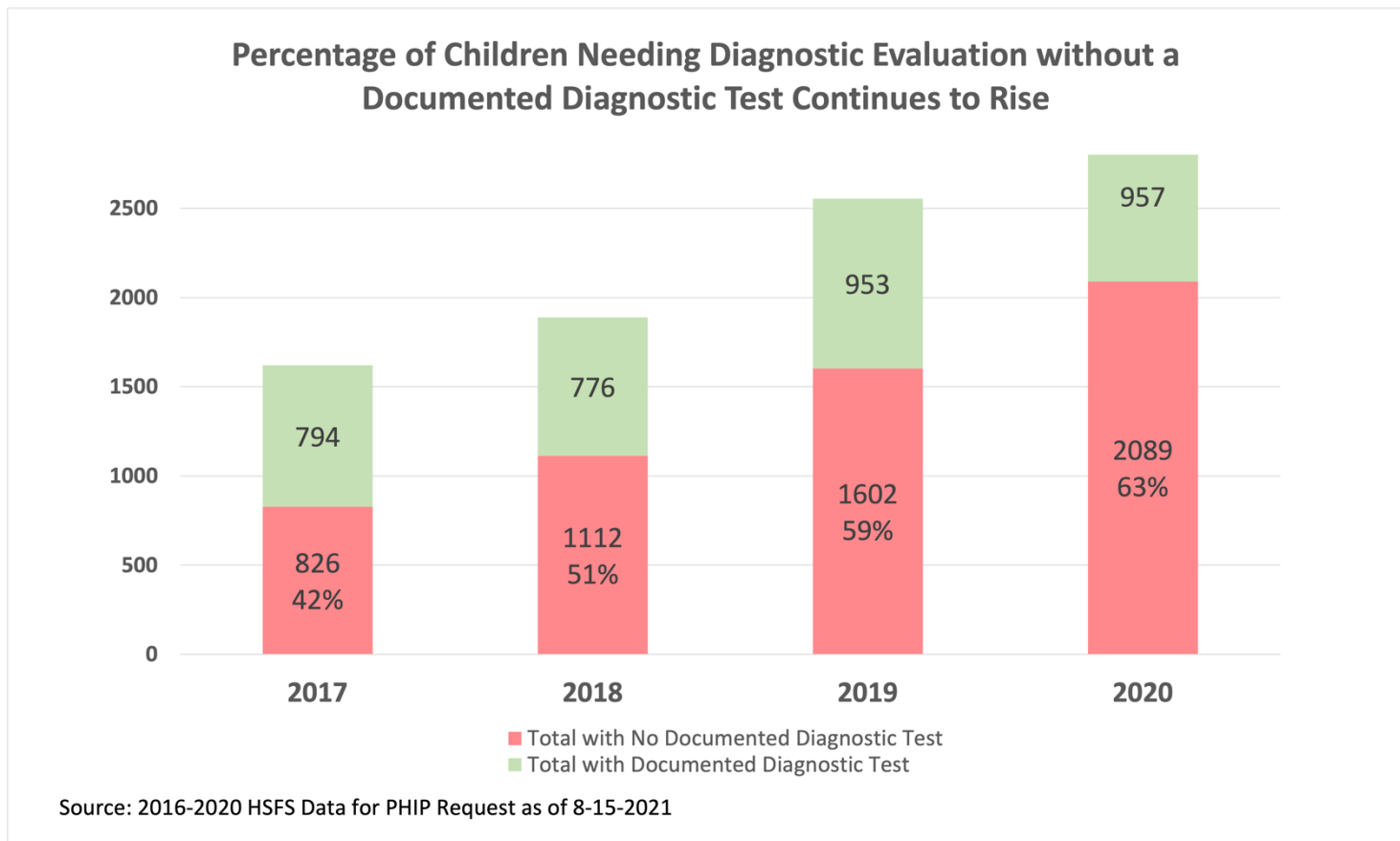
Of the infants who did receive a diagnostic evaluation, 30% received the evaluation *after 3 months of age*, putting them at risk for late enrollment into EI services. While late diagnosis is an issue in Georgia, this report focuses on the 68% of infants lost to follow-up (i.e., those who failed their Newborn Hearing Screening but are never reported as receiving a follow-up diagnostic test).

It is critical to note that the number of infants identified as needing a follow-up diagnostic test has increased by 88% over the past four years – from 1,620 in 2017 to 3,046 in 2020. This is due to EHDI efforts to improve the documentation of newborn hearing screening results and the timeliness of hospital reporting of these results. Prior to 2017, infants with no reported hearing screening status were assumed to be a passed hearing screening. Hospitals only reported results for infants who did not pass prior to mid-2015 under the assumption that all other infants passed. Requiring documented screening results for all infants regardless of test result has helped Georgia dramatically increase identification of infants needing follow-up screening as seen below.



Source: 2017-2020 HSFS Data for PHIP Request as of 8-15-2021

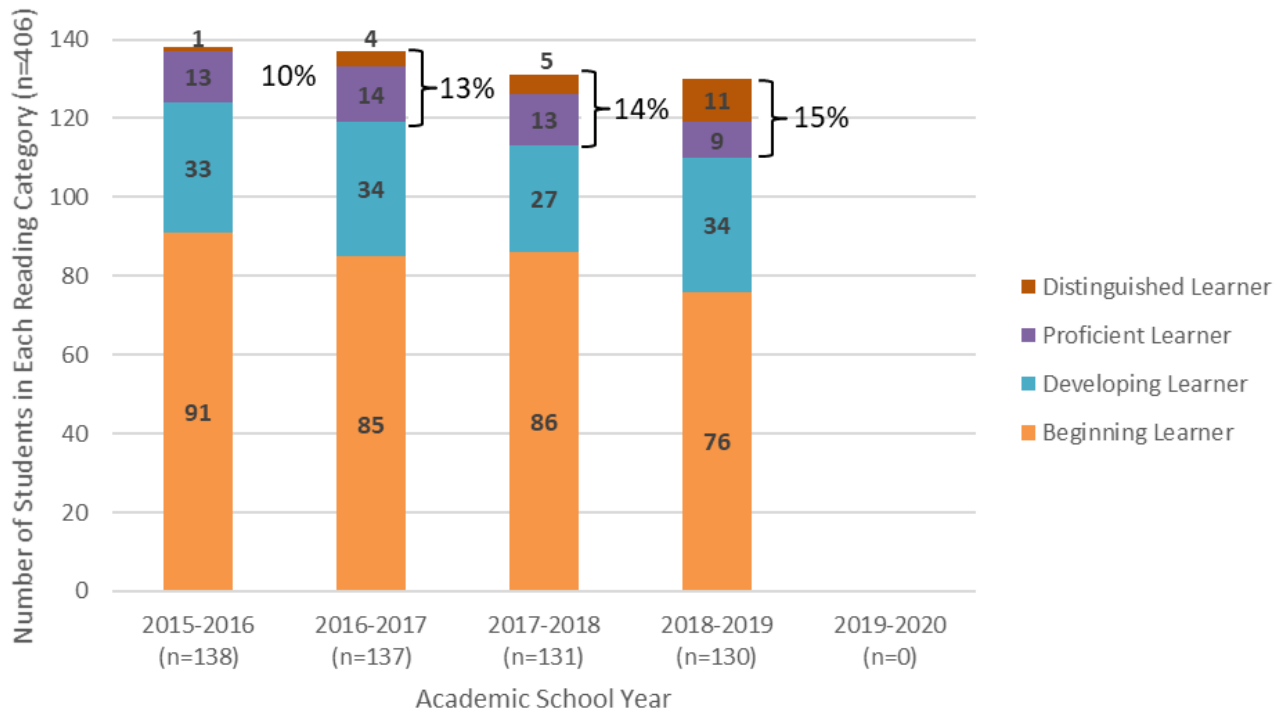
Diagnostic capacity is a contributing factor to the decline in on time diagnostic evaluations. For a more detailed discussion of the state’s diagnostic capacity, please see the Year 1 Annual report available at dhs.georgia.gov/gacdhh. Both the percentage and number of Georgia children reported as *never* receiving a diagnostic evaluation has increased significantly in the past four years – from 42% in 2017 to 63% in 2020. This highlights the state’s lack of capacity which was already stretched to the limit.



It is important to note that a relatively low percentage of infants who fail their newborn hearing screening will be diagnosed with hearing loss. When the CDC reports diagnostic rates, these rates convey the percentage of children who receive a diagnostic evaluation. This diagnostic rate does not indicate which infants were diagnosed as DHH and which infants were diagnosed with typical hearing. The CDC estimates the prevalence of pediatric hearing loss as 1.7 infants per every 1,000 infants screened at birth. Georgia’s prevalence of pediatric hearing loss was in 1.6 2017, 1.6 in 2018, and 1.7 in 2019, and 1.7 for every 1,000 infants for preliminary data in 2020, illustrating that Georgia has been on par with the national average even when follow-up was beginning to be impacted in 2019 by the COVID-19 pandemic.

This diagnostic dilemma begins as a public health crisis and morphs into an education crisis for Georgia’s children who are DHH as only 15% of Georgia students in special education with a primary eligibility of DHH read proficiently in the 3rd grade (see Georgia ELA Milestones Graph on the following page). Due to the lack of Milestone testing during COVID-19 data are not available for the 2019-20 school year.

Georgia's ELA Milestones Scores by Proficiency Category 3rd Grade Special Education DHH Students

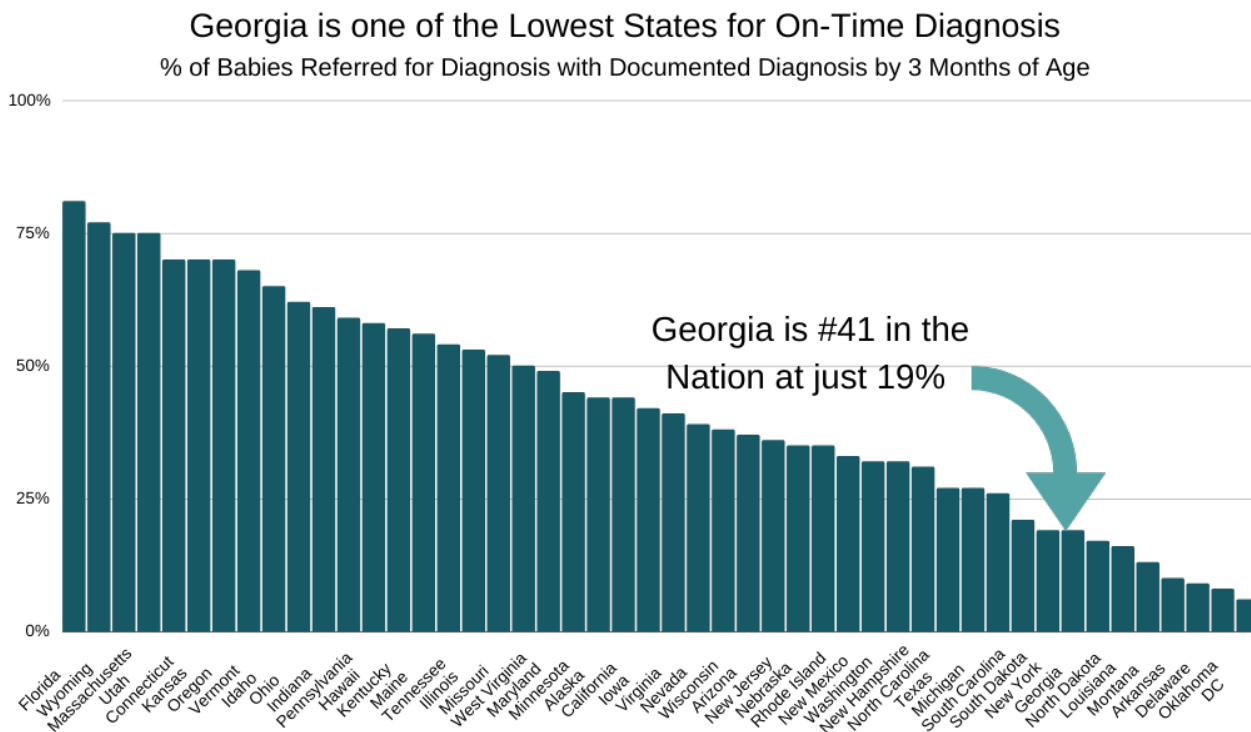


GA Diagnostic Rates compared to other states using CDC Data

Georgia's Diagnostic Ranking in the U.S.

Compared with other states' 2019 diagnostic data, Georgia is among the bottom ten performers in the nation. The graph below shows a state-by-state ranking based on the percentage of infants who failed the newborn hearing screening reported as receiving a diagnostic evaluation before three months of age. There is a wide variance in state performance with Florida having a notable on time diagnostic rate of 81%. To improve Georgia's performance, the state must drill down and identify specific factors that contribute (positively and negatively) to Georgia's diagnostic dilemma. The contributing factors analyzed below include race, maternal education, and age. These factors, which are often related to health outcomes, are often referred to as health determinants. National research shows that the negative effects of health determinants can be mitigated through public health policies and population-specific interventions. The state comparison below suggests that there are ways to mitigate risk factors associated with loss to follow-up. Georgia should investigate how states, like Florida, support access to and reporting of diagnostic evaluations to improve Georgia's diagnostic rate. It is important to note that states are diverse; each has its own unique demographics and resources and as such what works in one state may not be successful in another state.

It is also critical to note that federal funding for EHDI programming is currently capped at a maximum amount and does not take an individual state's birth rate into account.

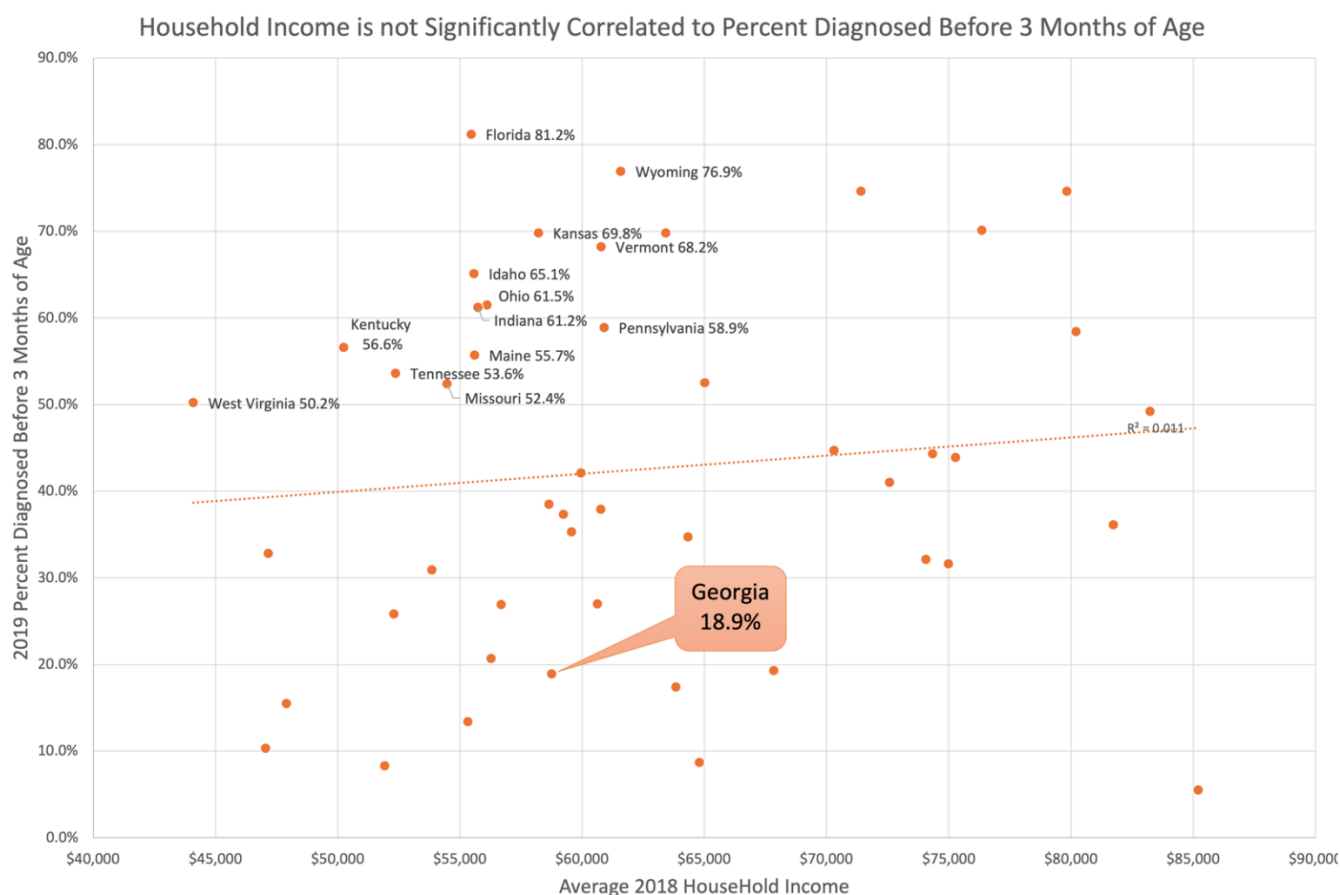


Source: 2019 CDC EHDI Hearing Screening & Follow-up Survey (HSFS). Includes cases of normal hearing and hearing loss. Alabama, Mississippi and Colorado did not report in 2019.

What Drives the Diagnostic Dilemma – Is it Household Income?

Household Income (HHI) is often identified as a significant contributing factor to Georgia's low diagnostic rate. Data were collected from the American Community Survey detailing average HHI for each state and were compared to the 2019 CDC/EHDI Hearing Screening & Follow-up Survey (HSFS) data shown in the previous graph¹². The results were surprising.

The data indicate that a state's average HHI is not a significant predictor of diagnostic rates. In fact, there are several states, many located in the Southeastern region, with significantly lower average HHIs and significantly higher on-time diagnostic rates than Georgia. The chart below identifies Georgia and several comparison states that defy the notion that a lower average HHI would predict a lower rate of on-time diagnostics. In fact, 17 states have lower average HHI than Georgia yet achieve higher on-time diagnostic rates – Florida (81.2%), Kansas (69.8%), Idaho (65.1%), Ohio (61.5%), Indiana (61.2%), Kentucky (56.6%), Maine (55.7%), Tennessee (53.6%), Missouri (52.4%), West Virginia (50.2%), Nevada (38.5%), New Mexico (32.8%), North Carolina (30.9%), Michigan (26.9%), South Carolina (25.8%) and South Dakota (20.7%). Georgia should investigate how these states support access to diagnostic evaluations to uncover potential methods for improving the state's diagnostic process.

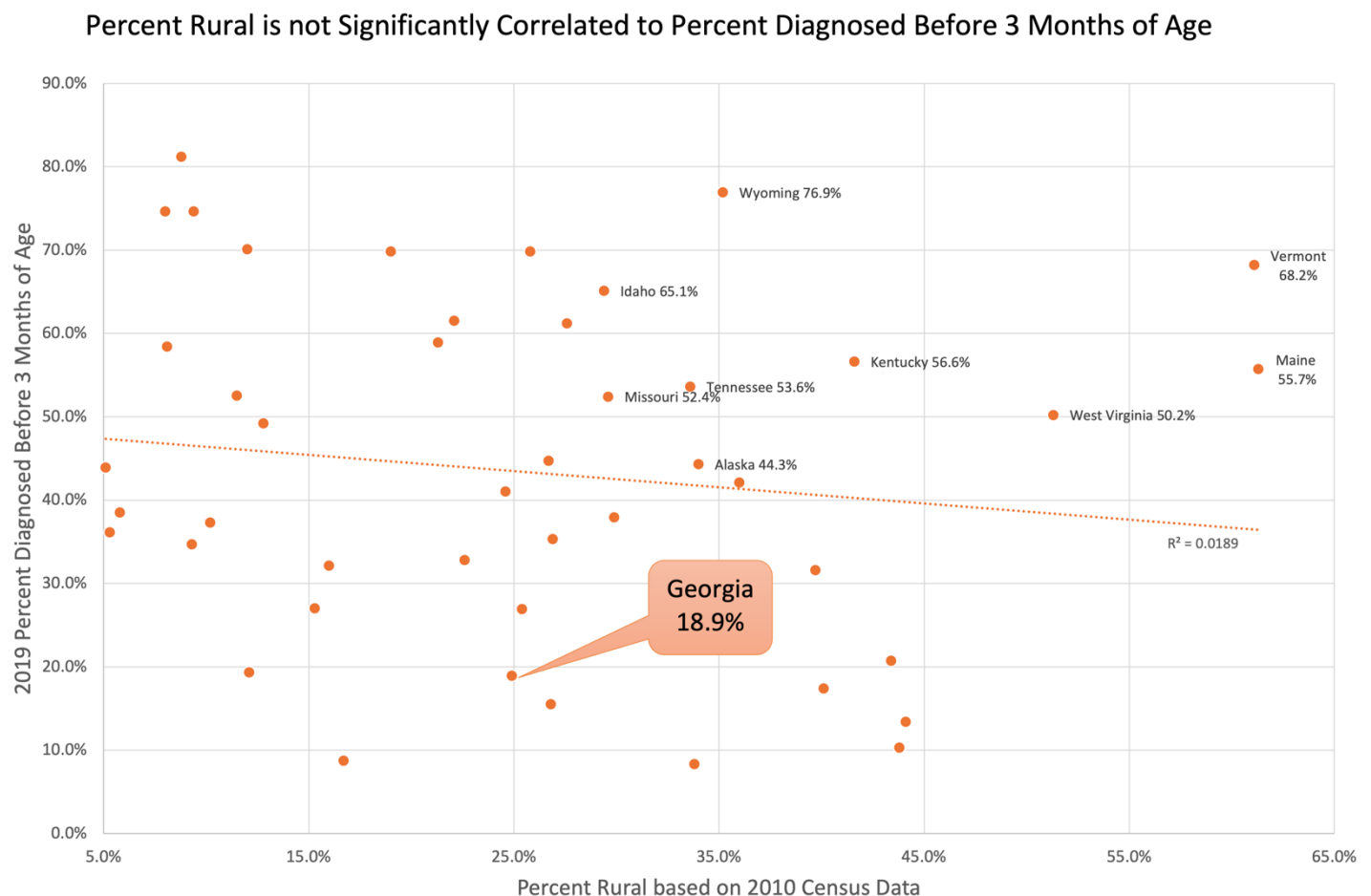


¹² "S1901: INCOME IN THE PAST 12 MONTHS (IN 2018 INFLATION-ADJUSTED DOLLARS)". *data.census.gov*. December 19, 2019. Retrieved December 20, 2019.



What Drives Georgia's Diagnostic Dilemma – Is it Driven by a State's Rural Composition?

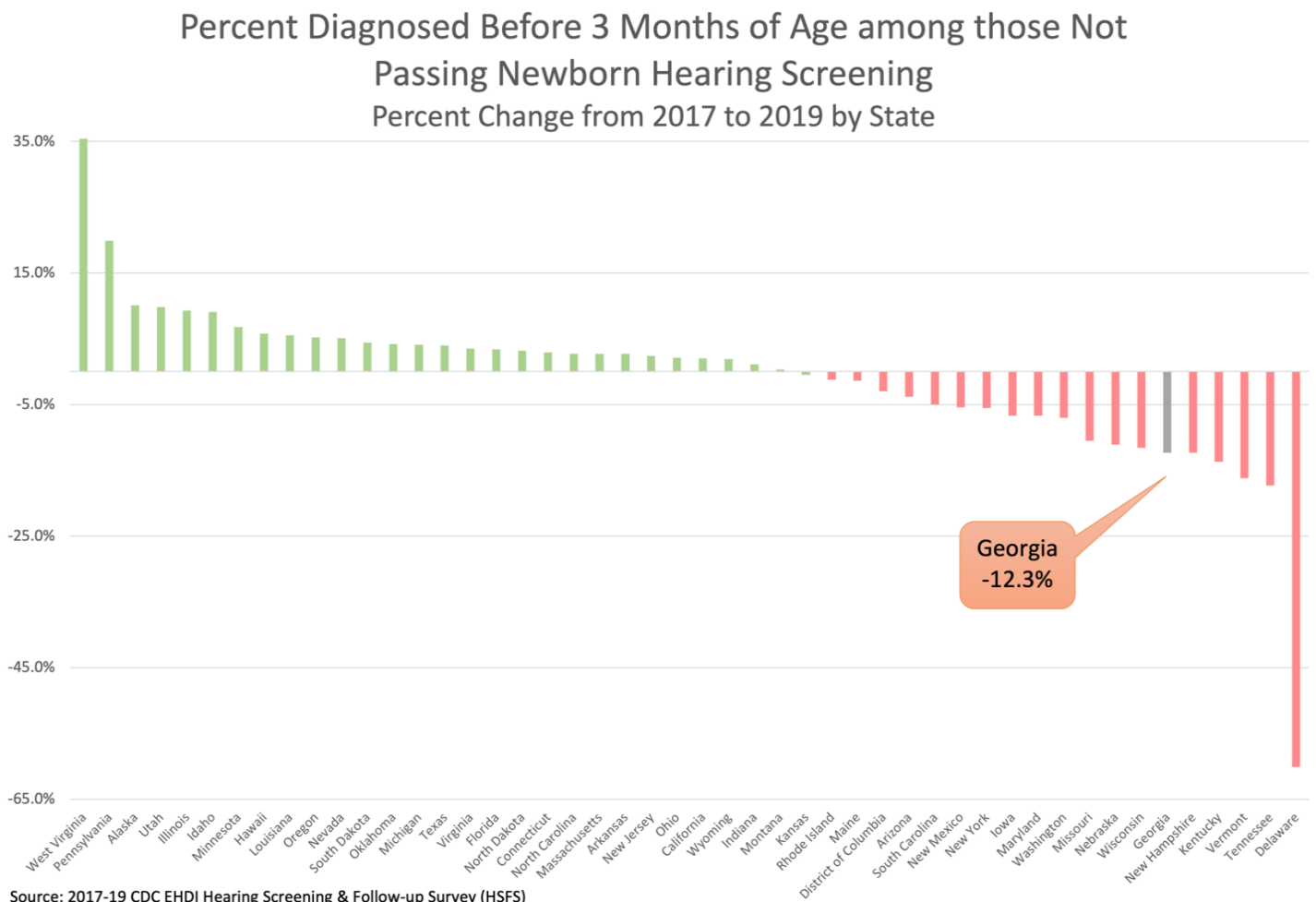
Another factor often connected to on-time diagnostic rates is a state's rural composition. The assumption is that states with more rural areas may have fewer local resources requiring families to travel long distances to access diagnostic services. The authors gathered data from the 2010 Census in which states' rural compositions were ranked by *World Population Review* to determine if rural composition was a predictor of on-time diagnostic rates¹³. Again, the data results were surprising in that rural composition did not predict on-time diagnostic rates. In fact, there are 20 states with greater rural compositions and higher on-time diagnostic rates than Georgia. These states include Wyoming (76.9%), Kansas (69.8%), Vermont (68.2%), Idaho (65.1%), Indiana (61.2%), Kentucky (56.6%), Maine (55.7%), Tennessee (53.6%), Missouri (52.4%), West Virginia (50.2%), Minnesota (44.7%), Alaska (44.3%), Iowa (42.1%), Wisconsin (37.9%), Nebraska (35.3%), New Hampshire (31.6%), North Carolina (30.9%), Michigan (26.9%), South Carolina (25.8%) and South Dakota (20.7%). These data show rural composition of a state is not a significant predictor of the rate of on-time diagnosis.



¹³ Lisa, A. (2019, April 8). States with the biggest rural populations. Stacker. <https://stacker.com/stories/2779/states-biggest-rural-populations?page=5>

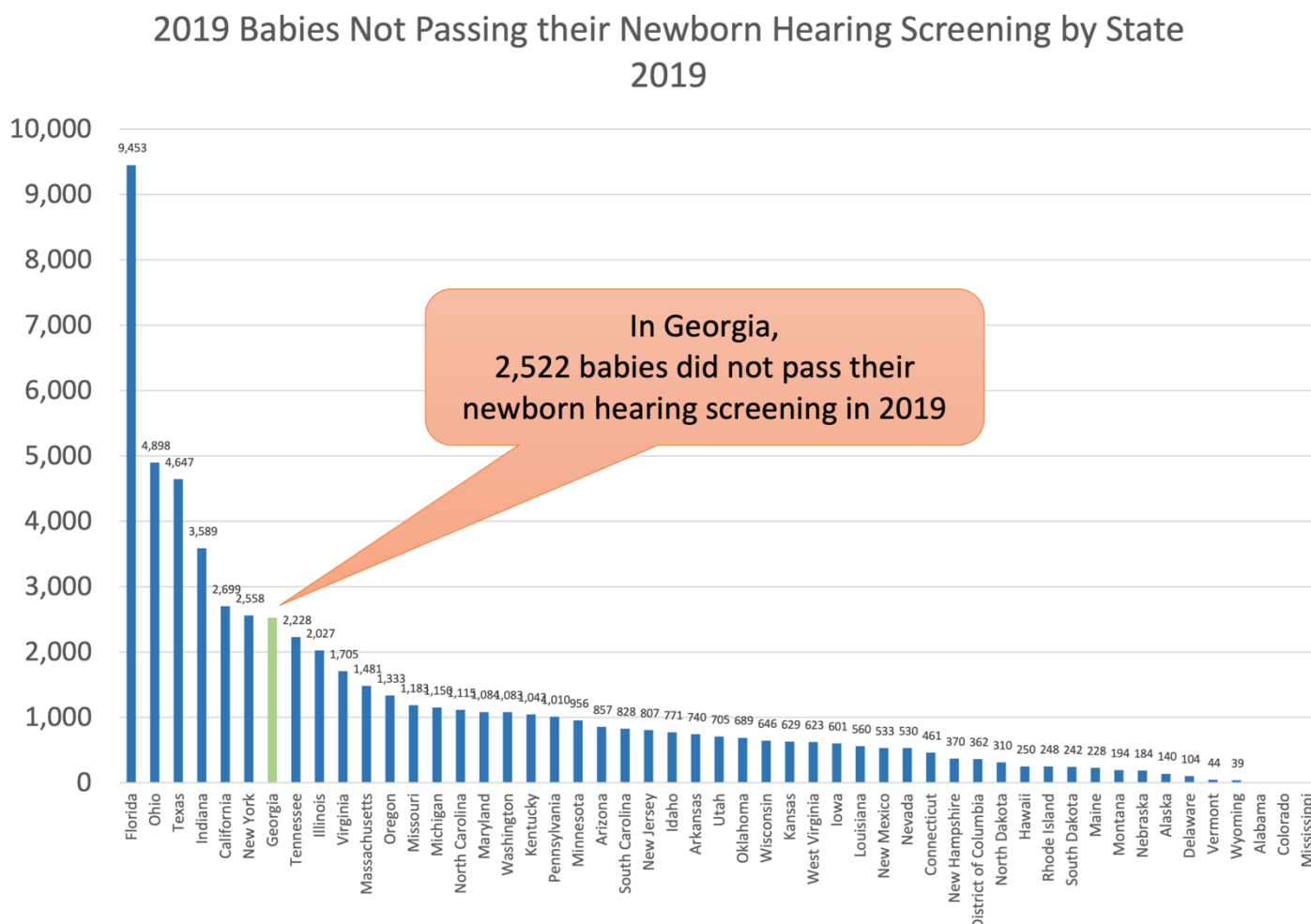
What Drives Georgia's Diagnostic Dilemma – Is Georgia's Rate of Diagnosis Improving?

The authors analyzed all states' diagnostic rates using data for 2017, 2018, and 2019 to determine whether there was a national decline or if Georgia's three-year decline in on-time diagnostics was specific to the state. Authors analyzed the diagnostic data from the 2017, 2018 and 2019 CDC HSFS and calculated the rate of change over the three-year period from 2017 to 2019 expecting to see a universal decline, however the data did not indicate a national decline. In fact, 29 states realized an increase in performance with West Virginia leading the nation with a 35.4% increase from 2017 to 2019. Georgia's 12.3% decline marks the state as one of the lowest performers in the nation over this three-year period (i.e., a state with one of the steepest declines over this period). It is important to note that the 2017-2019 data show Georgia to be one of the few states with a longitudinal (year over year) decline. This decline is due in large part to the improvements made in documenting the initial hearing screening status of every occurrent birth in Georgia. As mentioned earlier, infants with no reported hearing screening status were assumed to be a passed hearing screening until mid-2015. Requiring documented screening results for all infants regardless of test result has dramatically increased the number of infants needing follow-up testing.



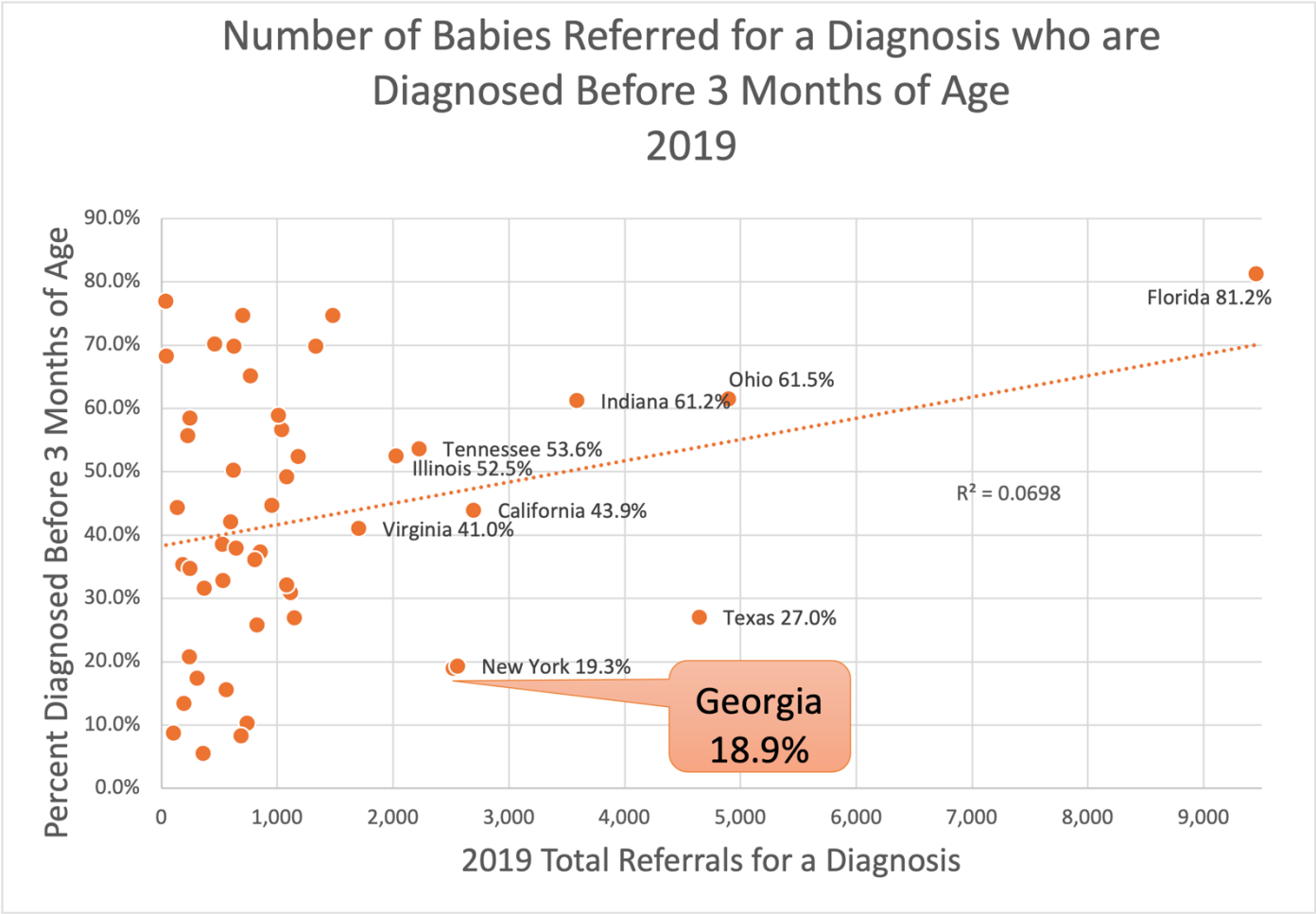
What Drives Georgia's Diagnostic Dilemma – Is it the Number of Infants Who Fail Their Hearing Screening?

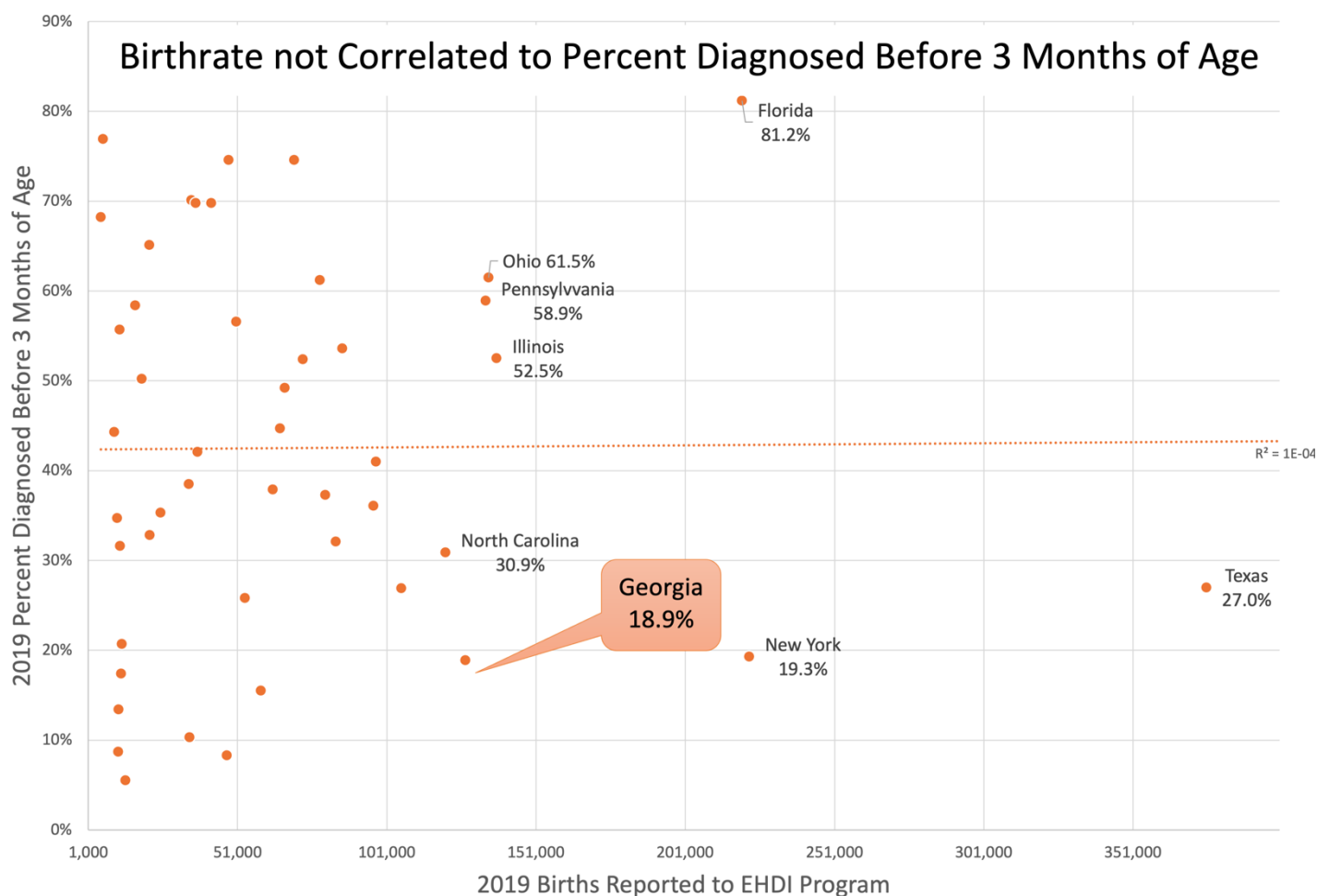
It is important to note that while the diagnostic rate in Georgia is comparatively low, the number of infants who fail the newborn hearing screening and therefore are referred for a rescreen and/or a diagnostic test is very high. With 2,522 infants not passing their newborn hearing screening in 2019, Georgia is one of the top 6 states in actual referrals for a diagnostic evaluation. While Wyoming boasts a 76.9% diagnostic rate, they had one of the smallest numbers of infants who failed their newborn hearing screening (n=39). The chart below illustrates the number of infants reported as failing their newborn hearing screening by state.



Therefore, the authors ran an analysis to determine if the number of infants referred for a diagnostic was a significant factor in predicting diagnostic rates. The working hypothesis was that states with a greater number of referrals may have lower diagnostic rates due to a larger number of infants moving from one transaction to the next (i.e., a capacity issue). Surprisingly, the opposite was true. The graph below shows that states with higher caseloads typically have *higher* diagnostic rates. Florida, California, Indiana, Ohio, and Texas all have a higher number of infants referred for diagnostic than Georgia, yet these states all have higher on-time diagnostic rates. Again, Florida stands out with 9,453 referrals and a diagnostic rate of 81.2%. It should be noted that not all states include the opportunity for a baby to receive an outpatient rescreen, as is Georgia protocol, prior to being referred to an audiologist for diagnostic testing. By allowing for an outpatient rescreen, the overall number of referrals made to an audiologist for diagnostic testing is reduced, which reduces the burden on the system, but it also

increases the time frame for scheduling a diagnostic appointment. There are advantages and disadvantages inherent to the protocols established at the state level.





What Drives Georgia's Diagnostic Dilemma? – Reasons Given for No Documented Diagnosis

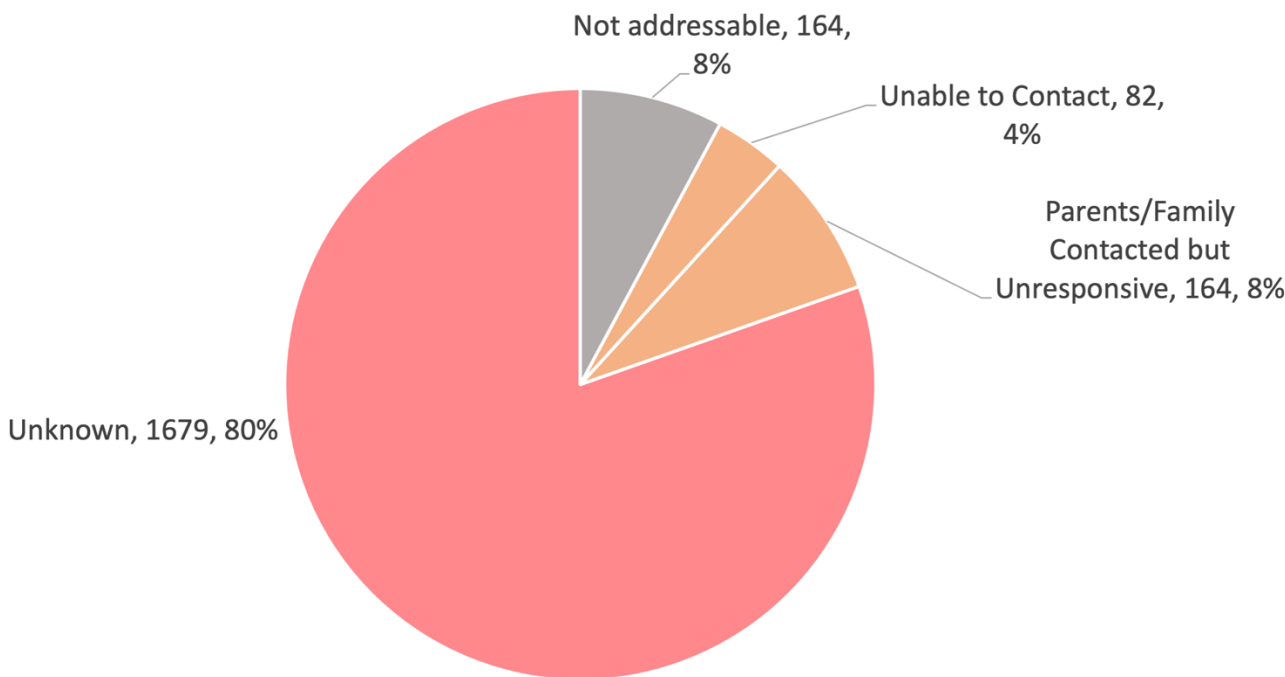
The EHDI Hearing Screening and Follow-up Survey (HSFS) provides an annual summary that includes the reasons a baby may not have a reported diagnostic evaluation. If a baby does not pass the initial hearing screening and is not reported to have a follow-up screen or diagnostic evaluation, the baby is considered lost to follow-up. Several lost to follow-up categories fall outside the scope of the state's DHH ecosystem. For example, if a family moves to a different state or has a baby with a medical reason for not receiving a diagnostic evaluation, providers within the ecosystem cannot reasonably conduct and record the diagnostic evaluation. For this report, we refer to these reasons as "not addressable".

The remaining reasons account for *the majority* of Georgia's not received/not reported diagnostic evaluations:

- Parents/family contacted but unresponsive
- Unable to contact
- Unknown

In 2020, there were 2,089 infants who failed the newborn hearing screening and who do not have a documented diagnostic evaluation. Of these, 164 are considered not addressable and fall into the following categories – In Process, Medical Constraint, Baby Died, Parents/Family Declined and Non-Resident/Moved. However, the remaining reasons are addressable. The chart below shows the reasons given for no documented diagnosis.

Little Data Regarding Lack of Reported Diagnosis
2020 Georgia Reasons for No Documented Diagnosis (N=2,089)



Source: 2020 HSFS Data for PHIP Request 8-15-2021

Data analysis indicates that 12% of the no documented diagnostic occurrences fall within parent engagement categories (i.e., parents/family contacted but unresponsive and unable to contact). Georgia’s EHDI program is in the process of documenting the parent engagement experience to identify areas for improvement.

Of great concern is the 80% of children without a documented diagnostic evaluation for which the authors have no identifiable reason (i.e., unknown categories). This percentage is equal to 1,679 infants; a substantial number considering the state identified 3,046 infants who failed their screening and needed a follow-up diagnostic test. It is impossible to improve a process/system if the state cannot identify why the process/system is underperforming. Georgia must continue to work to uncover the reasons for no reported diagnosis for the infants in the unknown category in the same manner that efforts have focused on improving documentation for infants with unknown hearing screening results which has been addressed since 2017 resulting in vast improvement in the referral process. The large number of infants in the unknown category may be due in part to data extraction protocols presently being used. The EHDI program will focus on infants that fall in the “unknown” category for further distinction during the next year. This may require adjustments to the current data collection, documentation, data reporting, and data sharing processes.

Surveillance of Hearing Loss in Early Childhood

Traditionally, ongoing surveillance for children who pass the initial hearing screening is not a component of the EHDI program. In recognition of the number of infants lost to follow-up and with the knowledge that the prevalence of hearing loss more than doubles between infancy and entry into the educational system, the EHDI program developed and is implementing a plan to expand the infrastructure for collecting and reporting on data for hearing screening for children up to age 5.

Georgia EHDI has plans to engage Maternal and Child Health Programs within DPH including Babies Can't Wait (BCW), Home Visiting, Children's Medical Services and other Title V programs working with children birth to three to assess the level to which they currently serve children who are DHH and their current process of care coordination. EHDI is leveraging the connections established and those being developed through the implementation of the Language and Literacy Initiative to connect with internal (DPH) partners and external (GaDOE, DECAL, GMA, Georgia PINES) partners. The resources developed through the Early Childhood Hearing Organization (ECHO) will be promoted and used to assist in establishing ongoing surveillance for children birth to three.

Although the EHDI database was not designed to capture data outside of 1-3-6 services, modifications were made to the database this year to enable audiologists to report results of surveillance and monitoring of audiological services provided to infants and young children. The database modifications allow for limited expansion of data collection and analysis to capture infants and young children with late onset or progressive hearing loss as well as attempting to capture those lost to follow-up.

Three primary activities were outlined to expand the capacity to support early childhood screening. The first activity was building the capacity for differentiating data in SendSS gathered from the EHDI program versus from ongoing surveillance of hearing status. In Georgia, hearing loss is a reportable condition and providers are mandated to report newly confirmed permanent childhood hearing loss for all children through age five. In the Diagnostic Test Results section of the EHDI module in SendSS, audiologists now have additional options in the "Reason for Evaluation" that reflect surveillance and monitoring. Similarly, for reporting results of hearing screenings conducted beyond the newborn hearing screening activities, a separate section was added to record results of hearing screenings conducted for young children for ongoing surveillance of their auditory status. EHDI has provided education to public health district staff and audiologists on the new options available within the database and the best way to record and report results to the EHDI program through the audiology portal.

The second activity outlined was to increase collaborations with GMA. GMA audiologists are working with the EHDI program to increase the availability of follow-up services to families in underserved areas and to assist with provider education and engagement.

The third activity outlined was to engage Maternal and Child Health Programs within DPH including BCW, Home Visiting, Children's Medical Services and other Title V programs working with children birth to three to assess the level to which they currently serve children who are DHH and their current process of care coordination. Initial education and presentations regarding the EHDI program and making referrals for infants

and young children with concerns about hearing were held for Home Visiting and Children's Medical Services. Collaboration between Part C and EHDI are underway to promote data sharing.

Georgia Testing Identification (GTID) Number Assignments

Since August 1, 2018, for each child through age five reported to EHDI with a permanent childhood hearing loss, the EHDI program requests a Georgia Testing Identification (GTID) number from GaDOE to facilitate monitoring progress of children who are DHH once they transition from infancy and early childhood into GaDOE services. GaDOE assigns a GTID to every child enrolled in the Georgia public school system. Once assigned, the GTID remains with the student as a unique identifier through high school. This number allows educators and evaluators to identify and map the progress of every child enrolled in public school. Through the Language and Literacy initiative, GaDOE is now able to assign GTIDs at the time hearing loss is diagnosed (several years before school entry). As of August, of this year, 961 children who are DHH have received a GTID through Georgia EHDI requests. This total includes infants and young children identified as DHH who were not born in Georgia but were Georgia residents at the time of identification. Additional steps as outlined by state and federal privacy statutes as well as program-based parent consent requirements are in development to share data among programs and agencies. The task force proposes that ongoing implementation will be necessary to utilize the GTID process. This process is in compliance with OCGA § 30-1-5 which will eventually allow public health professionals and educators to develop an individualized plan for every child who is DHH and to identify children at particular risk so that parent navigation and extra supports can be deployed to ensure on-grade level language and literacy.

Automated Referrals for EI and Family Support

In addition to requesting a GTID number for each child reported with a permanent childhood hearing loss, the EHDI program has automated the referral process to the state EI programs (BCW and Georgia PINES) and for family support through Georgia Hands & Voices. Once an audiologist reports a confirmed hearing loss, encrypted emails are sent to each program to coordinate care for service delivery to families. Automating the referral process reduces the likelihood of a missed referral and reduces the delays inherent in non-automated systems.

Demographics and Risk Factors Accompanying Lower Rates of Diagnosis

In the OCGA § 30-1-5 Year 1 Report, authors identified the need to break down specific risk factors (or health determinants) that may contribute to lower outcomes for children who are DHH. Demographic data (e.g., race, ethnicity) were also analyzed to understand their impact on diagnostic outcomes. These data do not address the timeliness of the diagnostic evaluation, rather they indicate whether a baby is recorded as receiving a diagnostic evaluation *at all*. Highlights from our findings are detailed below. Supporting graphs are also included.

In Georgia, socioeconomic factors are significant predictors of diagnostic outcomes. Below is a summary of socioeconomic risk factors and their impact on diagnosis. However, the state-by-state analysis above indicates that these factors can be mitigated.

- **Race** – Diagnostic rates of Black and Multiracial infants are 10-20 percentage points lower than infants of other races.
- **Maternal Education** – Diagnostic rates of infants born to mothers without a college degree are over 10 percentage points lower than infants born to mothers with a college degree.
- **Maternal Age** – Diagnostic rates of infants born to teen mothers are up to 15 percentage points lower than infants born to older mothers.
- **Public Health District of Residence** – The rate of infants with a documented diagnostic evaluation varies *greatly* by public health district ranging from only 20% in some districts to over 80% in highest performing districts. There is a vast disparity in outcomes depending on a family's district of residence. The disparity in outcomes by health district is due in large part to the lack of pediatric audiologists available to provide follow up audiological services to infants referred from EHDI (see more detail in the Year 1 annual report available at dhs.georgia.gov/gacdhh). In fact, Georgia has one of the lowest rates of certified audiologist to population ratios in the nation (ranked 43rd) with 3.4 audiologists available for 100,000 people¹⁴. At present, there are no graduate programs to educate audiologists in the state.
- **Insurance Status** – One of the biggest barriers to receiving a diagnostic evaluation and providing EI for children who are DHH is whether a family is privately insured, underinsured/high deductible plan, uninsured, or a Medicaid recipient. Many insurance companies do not reimburse for follow-up screenings. Many providers do not accept Medicaid patients due to low reimbursement rates. In addition, pediatric hearing aids and cochlear implants are not always fully covered by insurance and require families to pay significant out-of-pocket costs.
- **Other Factors** – Other risk factors include but are not limited to a family's access to transportation (public and private) and the child's age in months (older children who are not early identified as DHH are at the highest risk for language/literacy delays). It is very important to note that diagnostic testing for infants is best accomplished while the baby is asleep. "Nap" studies wherein the baby is in a natural sleep are generally successful for infants younger than 4-5 months old. Older infants, however, must be sedated as it is difficult for them to stay completely still for the test. When infants are not diagnosed by 3 months, the need for sedated testing to determine a baby's hearing status is often the case, and parents often are more

¹⁴ American Speech-Language-Hearing Association. (2021). Annual workforce data: 2020 ASHA-certified audiologist- and speech-language pathologist-to-population ratios. www.asha.org

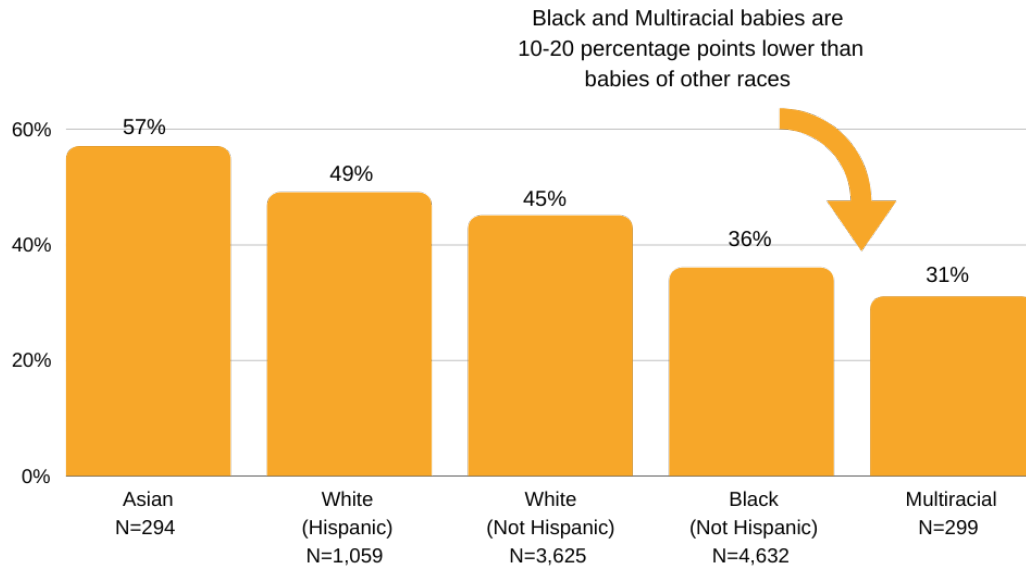


hesitant to complete testing when sedation is required. Parents of infants needing follow-up testing also report that they have received inconsistent messaging from health care professionals regarding the importance of receiving a timely hearing evaluation for their baby as some health care providers take an inappropriate “wait and see” approach to follow-up care for hearing concerns.



Race is Significant Factor in Receiving a Diagnostic Test

% of Babies Referred for Diagnosis with Documented Diagnosis by Maternal Race, 2016-2020

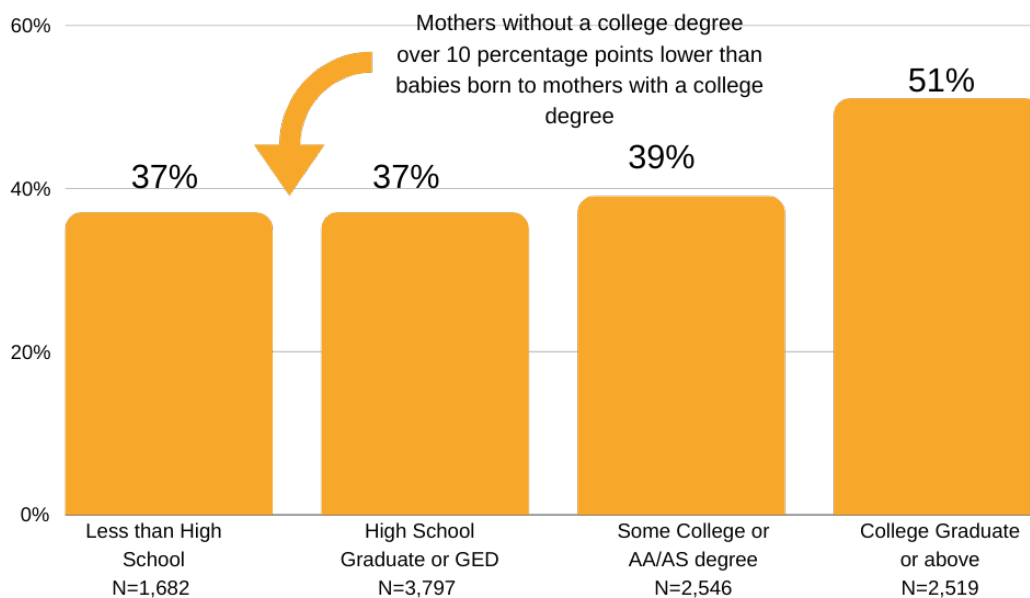


Source: 5 year aggregate 2016-2020 DPH/EHDI HSFS Data as of 8-15-2021

Note: Due to insufficient sample sizes, calculations could not be made for the following: Black or African American (Hispanic), Native Hawaiian or Pacific Islander, American Indian or Alaskan Native.

Maternal Education is Significant Factor in Receiving a Diagnostic Test

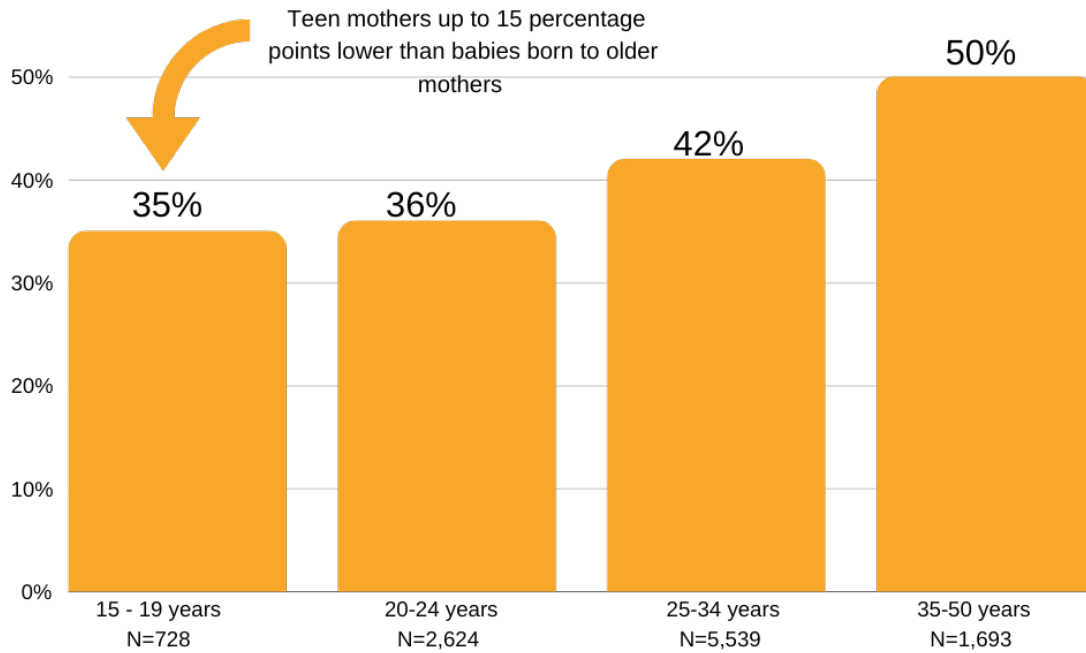
% of Babies Referred for Diagnosis with Documented Diagnosis by Maternal Education, 2016-2020



Source: 5 year aggregate 2016-2020 DPH/EHDI HSFS Data as of 8-15-2021

Maternal Age is Significant Factor in Receiving a Diagnostic Test

% of Babies Referred for Diagnosis with Documented Diagnosis by
Maternal Age, 2016-2020



Source: 5 year aggregate 2016-2020 DPH/EHDI HSFS Data as of 8-15-2021. Do to insufficient sample sizes calculations could not be made for the <15 years and >50 years categories.

Efforts to Improve Diagnosis and the Impact of COVID-19

The DPH's Early Hearing Detection and Intervention Program (EHDI)

The response to the COVID-19 pandemic continues to impact EHDI follow-up on children needing services throughout the state. As a public health response to the initial stages of COVID-19, Jeannine Galloway, Director of the Department of Public Health's Maternal and Child Health (MCH) Section, distributed a fax blast/communication to primary care providers throughout the state reinforcing that hearing screening was included in essential care services. In response to that effort, to date 94% of infants born in 2020 are reported as having received a newborn hearing screening by 1 month of age. This demonstrates a focused commitment and extraordinary impact during the COVID-19 pandemic, considering the national CDC benchmark is having 95% of infants screened at birth by 1 month of age.¹⁵

Throughout the public health response to the pandemic, both state and district EHDI staff were deployed to COVID-19 associated activities. Georgia's 159 counties are divided into 18 health districts with a designated EHDI coordinator in each district to facilitate follow-up and assist with care coordination for families of infants who do not pass the initial hearing screening as well as those diagnosed with hearing loss. District EHDI staff were being redirected from EHDI activities for a range of a few hours a month to full-time deployment for more than a year.

Despite the COVID-19 pandemic, Georgia is on track to meet or exceed the first EHDI benchmark of maintaining a screening rate of greater than 95% by one month. In addition to EHDI staff being deployed to other activities, many outpatient facilities were closed or experienced restricted hours during the height of the public health emergency. Most hospital-based audiology programs remained available to families of infants needing follow-up in metropolitan areas, but many families living in rural areas of the state had no options open in their district to receive follow-up testing for infants that failed the initial hearing screening during the height of the public health response.

A disposition status specific to follow-up impacted by COVID-19 was added to the EHDI module within the State Electronic Notifiable Disease Surveillance System (SendSS) database to facilitate tracking. Continued efforts are underway to recapture these infants, including additional outreach and education regarding the importance of follow-up to Georgia's primary care physicians through webinars conducted by Dr. Paula Harmon, the EHDI Chapter Champion for the Georgia Chapter of the American Academy of Pediatrics and by EHDI and Babies Can't Wait (BCW) staff (BCW is Georgia's Part C EI program that offers a variety of coordinated services for infants and toddlers with special needs, from birth to three years of age and their families). The webinars reached 191 individual health care providers in Georgia and focused on the role of the medical home provider in the EHDI system, provided contact information for district EHDI staff, the location of follow-up service providers in each district, the impact of hearing loss on language and literacy, and state EHDI protocols.

During the pandemic response, EHDI also collaborated with other programs in MCH and the DPH Office of Quality, Performance, and Accreditation to develop an EHDI Service Delivery Process Map. This map (see Appendix D - Figures 1-3) was designed to be used as a resource for MCH stakeholders, medical home providers and other stakeholders involved in MCH to outline protocols, processes, and data flow. It is anticipated that the maps generated will facilitate care coordination between EHDI and other MCH programs with medical home

¹⁵ Georgia Department of Public Health. *Hearing Screening Data 2016-2020 – 2021 HSFS Data for GaDOE PHIP Request as of 8-12-2021.*

providers. In the initial stages of the public health emergency response (March 2020), a designated disposition status was added to the state tracking database to identify infants documented with follow-up being interrupted by COVID-19 and facilitate concentrated follow-up activities for those affected. At this time, of the more than 325,000 infants born in Georgia since 2019, 126 infants remain as needing follow-up testing specific to the impact of COVID-19. This number is an underrepresentation of the overall impact of the pandemic but allowed EHDI state and district staff to focus additional follow-up actions and activities for these infants and their families. Regardless of the challenges to service provision over the last year, EHDI identified and provided referrals to EI and family support services for 316 infants and young children reported as DHH during that time, and through EHDI's partnership with the Auditory Verbal Center (AVC), 40 hearing aids were loaned to 23 children.

On a positive note, during the COVID-19 public health response, EHDI noticed an increase in communication and collaboration between EHDI and the two largest pediatric audiology providers in the state, Children's Healthcare of Atlanta (CHOA) and Pediatric Ear, Nose, and Throat of Atlanta (PENTA). Both practices were instrumental in providing follow-up diagnostic services to the best of their ability during the pandemic for families that were able to travel to their facilities. PENTA also responded to the need for timely service provision for families by offering telemedicine visits for infants identified as DHH during the pandemic that needed clearance for hearing aids or consultations with families regarding cochlear implant candidacy. Anecdotally, a few infants now confirmed as DHH were possibly identified at an earlier age as they were referred directly to audiology for a diagnostic evaluation rather than receiving an outpatient rescreen.

One additional approach that EHDI has promoted to facilitate access to services is expanding teleaudiology services. There are only 30 known audiology practices skilled in infant diagnostic assessments in the state, and more than half of those are in the Metropolitan Atlanta Area. Several health districts in Georgia have no infant assessment facilities in their district and families often must travel long distances and sometimes stay overnight for the diagnostic evaluation. Prior to the pandemic, EHDI had established teleaudiology clinics in two underserved areas of the state (Waycross and Valdosta health districts) to increase access to infant assessment services in collaboration with audiologists from CHOA. More recently, GaDOE's Georgia Mobile Audiology (GMA) is also available to provide statewide teleaudiology services. In 2020 and 2021, Valdosta has seen 34 infants for infant assessments with 4 confirmed with permanent childhood hearing loss (i.e., 3 infants were diagnosed by CHOA audiologists and 1 baby was diagnosed by GMA). Service delivery is on pause currently at the Waycross location due to concerns that the audiology equipment is not compatible to preferred technology and is intermittent in providing the best results.

DPH received funding from the Association of Maternal and Child Health Programs (AMCHP) Coronavirus Aid Relief, and Economic Security (CARES) Act that assisted in the purchase of necessary equipment to provide infant assessment services in a third clinic in the Rome health district in Northwest Georgia. Increased access to audiological services will result in more timely identification of children that are D/HH and will reduce loss to follow-up.

Infants that are diagnosed with hearing loss by three months of age and connected with EI by 6 months of age have better language outcomes than those that do not meet these benchmarks. EHDI is collaborating with the GaDOE's GMA to provide training for personnel at and expansion to additional sites throughout the state. Due to Georgia EHDI's experience in this area, the program worked with other subject matter experts throughout the duration of the project, predominantly those provided through the HRSA National Training and Technical Assistance Partners (NTTAP) namely the National Center for Hearing Assessment and Management (NCHAM). As a member of the NTTAP Steering Committee for Teleaudiology services, established through AMCHP

funding from the CARES Act, technical assistance was provided to other audiologists throughout the nation that were interested in establishing teleaudiology services. Georgia's EHDI program provided 6 webinars and 4 virtual panel discussions over the last year. In total, the NCHAM teleaudiology CARES project reached 111 pediatric audiologists and 93 audiology facilities in 32 states, and 6 state EHDI systems were provided with some type of pediatric teleaudiology training and/or technical assistance. At the completion of the project, a final NTEC webinar on teleaudiology providing an overview of the project and the materials developed during the project period reached 86 participants throughout the country, including 4 from Georgia.

Quality Improvement

Quality improvement (QI) initiatives are an integral part of the EHDI system to ensure that guidelines, protocols, and processes are providing the foundation for a sound program. EHDI has implemented a process for providing quarterly performance reports for each of the 18 public health districts in the state regarding their progress towards meeting the EHDI 1-3-6 benchmarks. The performance reports are shared with the districts highlighting their rank in the state (top third, middle third, or bottom third) with percentages of infants meeting benchmarks for each goal and state averages for comparison. Districts not reaching benchmarks are provided one-on-one sessions to target areas for improvement. Quarterly reviews allow for more timely feedback and assist in providing Technical Assistance to district staff when warranted. Monthly checks for data entry errors and data outliers are also scheduled to improve data quality. When possible, weekly and monthly data transfers between different databases and SendSS are scheduled with Information Technology such as uploading out of hospital births (home births and birthing centers) and records of deceased infants from Vital Records.

One specific QI project conducted during the project period examined missing screening data for a two-week period, 6 months beyond the birth dates for the selected data analysis. Of note were the percentage of infants who were in the Neonatal Intensive Care Unit (NICU) for whom hearing screening results data were missing. Georgia hospitals submit hearing screening results on a NBS Card along with a dry blood spot and cardiac screening results. Due to the reporting protocols in Georgia, many infants needing special care or not medically stable at the time the blood spot collection is submitted to the DPH laboratory for analysis and data entry. Although a delayed screening report form and processes are in place to capture those infants, data indicated that this step was not completed in many hospitals. Results of the missing screening data were shared with state and district EHDI staff, protocols were reviewed, and hospitals were contacted as a reminder of the expectations for submission of results. For another QI project underway, EHDI is collaborating with critical congenital heart disease (CCHD) and dry blood spot screening programs to develop a hospital report card highlighting data accuracy and completeness. It is anticipated that providing feedback on the number/percent of infants who are missing results in the state database will promote better reporting to improve their report cards.

Georgia Mobile Audiology – Leveraging Teleaudiology

Georgia Mobile Audiology (GMA) is funded by the Georgia General Assembly via the GaDOE's State Schools Division. It is charged with addressing the shortage of available pediatric audiology services in the state. Both newborn hearing screening follow-up via otoacoustic emissions screening (OAE) and diagnostic non-sedated Auditory Brainstem Response (ABR) evaluations are currently available at no cost to the family through GMA. GMA employs two full time pediatric audiologists, a family engagement specialist in South Georgia, and an audiology assistant in the Macon area who can diagnose infants on site and via teleaudiology. GMA has a fully equipped mobile van capable of providing these services statewide. In addition, EHDI has recently contracted

with GMA to provide training to EHDI district coordinators. GMA is also working with the Regional Education Service Agency (RESA) in the middle Georgia/Dublin area to provide diagnostic services to school-aged children.

While GMA was temporarily shut down during the pandemic (March to October of 2020), they have been able to provide the following services:

- 3 – Newborn Hearing Screenings for infants who were not able to receive one in the birthing hospital
- 57 – Non-sedated diagnostic ABRs (31 in the Fulton County area due to a partnership with EHDI Hearing clinic in Fulton as part of the development of GMA’s capacity for performing teleaudiology)
- 7 – Infants diagnosed with hearing loss and referred to EI
- 24 – Hearing screenings for school-aged children
- 400+ families – received hearing aid batteries via partnership with the Jason Cunningham Charitable Foundation
- Current no show rate of 2% compared to national average of 25%
- 3 EHDI coordinators have referred in 2021

Most of these infants are seen as a direct result of the collaboration between the Valdosta area EHDI coordinator and GMA’s test assistant. This year, referrals have come from 3 of the 18 public health district EHDI coordinators. If this coordination model can be expanded statewide, this should significantly improve Georgia’s diagnostic rate. An official partnership between EHDI and GMA (including direct referrals from all 18 EHDI coordinators when appropriate) is critical to leverage this teleaudiology capacity. From January 2020 to present, GMA has seen 60 infants for follow-up infant testing. More information about Georgia Mobile Audiology can be found in Appendix E.

Access to Language – Providing Navigation for at Risk Families

Access to Language (AtL) is a program developed by the Atlanta Speech School and privately funded by the Oberkötter Foundation. AtL helps at-risk families navigate insurance and Medicaid processes, access financial resources, schedule diagnostic appointments, attend diagnostic appointments through transportation programming and access interpreting services. A parent navigator explains “what happens next” after a baby is referred from the newborn hearing screening to a follow-up screen or diagnostic test. The program began in Grady Hospital and has created online training modules for parent navigators, newborn hearing screeners and a teleaudiology manual for providers. These services are critical, especially considering the socioeconomic risk factors detailed above and their impact on a baby receiving a follow-up rescreen or diagnostic evaluation by 3 months of age.

In total, the AtL program has provided the following services:

- 99 infants born at Grady hospital failed their NHS and were referred for a follow up diagnostic test
- 98 of these infants received a follow up diagnostic test (1 infant was lost as the navigator could not get in touch with the family)
- 94% of these diagnostic tests were conducted by 2 months of age
- 5 of the 99 infants were diagnosed with permanent hearing loss and 3 were found to have conductive loss
- 38 families received transportation programming through ride sharing vouchers



A Model for Moving Forward – Collaboration and Teleaudiology/Teletherapy

As stated above, the COVID–19 pandemic has resulted in private and public professionals changing the way they deliver services to meet the needs of children. However, language and literacy achievement for these children continues to be a major crisis. While collaboration between state agencies and private entities has increased, there is a critical need to improve this collaboration as there are many different diagnostic services available throughout the state but a significant lack of service coordination. The following public/private services exist as their own separate programs (often with separate websites, etc.) making the DHH diagnostic ecosystem nearly impossible for a family to navigate.

For Screening and Diagnosis:

- 80 birthing hospitals that conduct newborn screening programs and 2 birthing facilities that refer parents to other facilities to have their infants tested
- Several third-party contractors who conduct newborn hearing screenings in birthing hospitals
- Private, standalone audiology clinics such as Children’s Healthcare of Atlanta (CHOA), Hearing Doctors of Georgia, Columbus Speech and Hearing Center, and Georgia Hearing Center
- Audiology in association with Ear, Nose, and Throat (ENT) physician practices such as Pediatric Ear, Nose, and Throat of Atlanta (PENTA), Wellstar ENT, and Whitley Pediatric ENT
- University-based clinics such as the University of Georgia’s Speech and Language Clinic and University Hospital in Augusta
- Georgia Mobile Audiology currently available in the Valdosta area and metro Atlanta with planned expansion in Macon via teleaudiology (and statewide if the GaDOE’s GEER-II teleaudiology grant is funded)
- EHDI Coordinators in the 18 public health districts, some who conduct outpatient screening if a baby is under 3 months of age and equipment is available, some who conduct diagnostic testing through a contract audiologist (Fulton, Gainesville).
- The Atlanta Speech School’s Access to Language Parent Navigation Program

There must be greater collaboration among service providers and state agencies so that services can be delivered in a more efficient, effective, and coordinated manner. This ongoing collaboration (including data sharing) would reduce duplication of effort and help to identify service gaps more accurately. The current DHH ecosystem is not child/family focused. Increased collaboration would maximize efforts and propel the state towards improved diagnostic outcomes.

The GaCDHH recommends convening the multiagency task force, as stipulated by OCGA § 30-1-5, to focus on the barriers to diagnosis detailed in this report.

Georgia Commission for the Deaf and Hard of Hearing (GaCDHH) Recommendations

Proposed Legislative Initiatives

Per OCGA § 30-1-5, the Georgia Commission for the Deaf and Hard of Hearing (GaCDHH) is charged with recommending legislation to Governor Kemp and the General Assembly that will improve the lives of Georgia individuals who are DHH. There are several significant legislative barriers which can be addressed by Governor Kemp and the General Assembly as follows:

1. OCGA § 43-44-7 language which restricts infant screenings
2. OCGA § 31-1-3.2 and 31-12-2 Non-Compliance
3. OCGA § 31-1-5 amendments

OCGA § 43-44-7 – Professional Requirements for Hearing Screenings

OCGA § 43-44-7 (h) stipulates that a person who is not licensed as an audiologist may perform nondiagnostic electro-physiologic screening of the auditory system, using otoacoustic emissions or auditory brainstem response technology, as part of a planned and organized screening effort for the initial identification of communication disorders in infants under the age of three months. However, this is not permitted after a baby is over three months of age. This creates a significant barrier to service as there is documented lack of pediatric audiologists across the state. The statewide lack of service providers is especially problematic for families in rural areas who must travel long distances for this relatively simple test. Other states do not have this restriction and it is certainly impacting Georgia's diagnostic rate.

In public health districts, OAE equipment may be present but without an audiologist it is unable to be used. EHDI coordinators are not licensed audiologists and therefore cannot use the testing equipment on any baby over three months of age. There are also instances where OAE equipment is available in a public school but there is not an audiologist on staff. The GaCDHH supports and respectfully requests that Governor Kemp and the General Assembly carefully consider legislation that will eliminate the restriction to testing infants under three months of age which is consistent with best practices and other state laws, especially given the fact that infants born during COVID-19 who lack a reported diagnosis are already 8 months to 2 and a half years of age. The GaCDHH recommends that subject matter experts convene as part of the multiagency task force to review and make suggestions to OCGA § 43-44-7 and to include requirements for reporting per OCGA § 31-1-3.2 and 31-12-2 as detailed below.

OCGA § 31-1-3.2 and 31-12-2 Reporting Non-Compliance

The current law requires that birthing hospitals/centers report hearing screening results on every infant. The law also requires that the results of all diagnostic hearing evaluations be reported within seven days. In 2019 only 63% of providers complied with this law. In 2020, this increased to 68% due to many efforts of the EHDI program.

It is critical that providers are timely in their report of initial screening results and that audiologists report children with confirmed hearing loss to the DPH within the mandatory seven-day window so that parents can receive timely access to EI as diagnosis is the entry point into the Georgia DHH ecosystem. Without a diagnosis of hearing loss, children who are DHH and their families are not eligible for EI or later school-age services specific to children who are DHH.

More detail on OCGA § 31-1-3.2 and 31-12-2 and EHDI efforts to remediate this issue is in Appendix F. SendSS compliance is a key data collection gap which should be carefully studied by the multiagency task force. Simply put providers are not following the law and any assistance the governor and General Assembly can provide would be great appreciated.

OCGA § 30-1-5 Amendments

To amend OCGA § 30-1-5 as follows:

- Extended term limits for the GaCDHH Commissioners from 3 to 4 years
- Removal of term limits for members of the Multiagency Task Force
- Extend due date of the legislative report to the end of the calendar year in accordance with the availability of DPH and GaDOE data

GEER II Grant Funding Requests

To remediate the effects of COVID-19, the Federal Government is allocating \$4.8 billion to the state of Georgia. These funds will be allocated by the governor. Two grant proposals will immediately address diagnostic and EI gaps affecting infants born in 2019 and 2020.

1. GEER II GA-0008050 The GaDOE Georgia Mobile Audiology Tele/Mobile Audiology Effort
2. GEER II GA-0008447 The AVC Teletherapy Expansion Effort

GEER II GA-0008050 Tele/Mobile Audiology Effort

The GaDOE's Georgia Mobile Audiology program recently submitted a proposal to the Governor's Emergency Education Relief Fund II (GEER-II) to expand teleaudiology services to reach infants lost to follow-up during COVID-19. This proposal requires collaboration and direct referrals from the DPH's EHDI coordinators.

The Early Hearing Detection and Intervention (EHDI) Team Lead and the EHDI Coordinators from Georgia's 18 health districts will coordinate with the GMA team and the Parent Navigation team to collect and input data related to child/family services, referrals, and testing results. EHDI coordinators will report on hospital compliance via quarterly reporting.

Performance Goals Metrics:

- Goal #1: Contact families who missed audiology services due to COVID-19 (born in 2019 and 2020); contact primary care physicians (PCPs)
 - Metric #1a: Number of families contacted by DPH/GaDOE
 - Metric #1b: Number of PCPs contacted by DPH/GaDOE
- Goal #2: Provide follow-up teleaudiology services for families within a 2-hour driving distance of their residence (including screening, diagnostic)
 - Metric #2: Number of families receiving teleaudiology services
- Goal #3: Provide wraparound services for families who are at high risk for loss to follow-up (e.g., transportation assistance, appointment setting, care coordination)
 - Metric #3a: Number of families receiving wraparound



- Metric #3b: Number of hours of support and/or number of contacts per family
- Goal #4: Train new audiologists and audiology technicians in teleservice provision
 - Metric #4a: Number of trainings completed
 - Metric #4b: Number of professionals completing training

Additional aggregate data may be used to evaluate the success of the program. The GaDOE will collect and report on the following data. Note that sample sizes less than 5 per DPH and 15 per GaDOE will be suppressed to comply with HIPAA and FERPA regulations to preserve the identity of the child/family. These data will be published on a quarterly basis and will be reported by public health district and teleaudiology zone when possible. The GaDOE will request these data pulls from the DPH EHDI Team lead quarterly. The GaDOE will also provide comparison data from the teleaudiology program's TIMS database to further evaluate data accuracy from various agency efforts and to determine collaborative success.

- Total number of referrals from the EHDI program coordinator
- Number of rescreens given each quarter
- Number of full diagnostic tests each quarter
- Aggregate number of children diagnosed with hearing loss
- Median days from referral to GMA to rescreen and/or diagnostic completion
- Age child is referred to EI services

The Oberkotter Foundation has provided written support of their intent to provide partially matching funds towards the Atlanta Speech School's Access to Language Parent Navigation program and parent and professional training modules. Below is a complete list of supporters of this grant proposal:

- The Georgia Department of Public Health
- The University of Georgia's Speech and Hearing Clinic
- The Atlanta Speech School's Access to Language Parent Navigation Program
- The Georgia Commission for the Deaf or Hard of Hearing (GaCDHH)
- The Jason Cunningham Charitable Foundation
- Pediatric, Ear, Nose and Throat of Atlanta (PENTA)
- Auditory Verbal Center of Georgia
- Georgia Lions Lighthouse
- Wellstar Healthcare
- Oberkotter Foundation (with partial matching financial contribution)

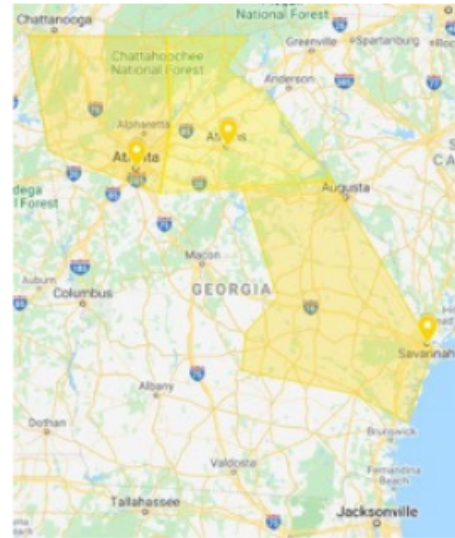
This private/public collaboration could be a literal gamechanger in improving diagnostic rates across the state. It is unique in its design and unlike any collaboration in the country. If awarded, immediate collaboration between the DPH and the GaDOE will be required to ensure that every baby born in 2019 and 2020 who failed their newborn hearing screening without a reported diagnostic test is referred to the GaDOE's GMA program. More information about this grant can be found in Appendix G.

Proposed statewide rollout of teleaudiology services upon approval of this grant is below:

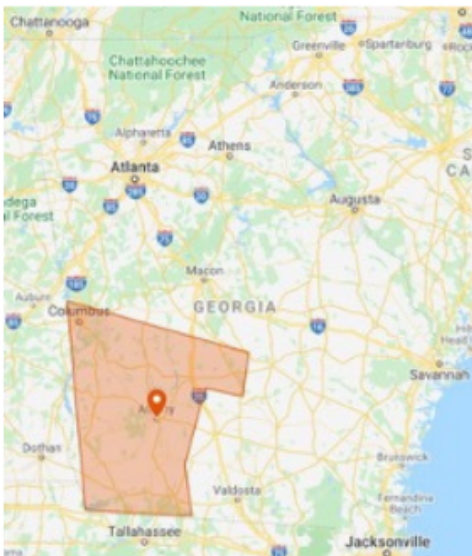
Current Service Map (2021)



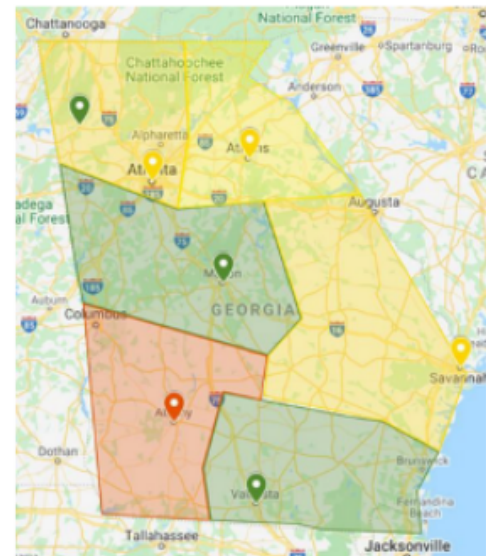
Proposed Expansion (Phase I)



Proposed Expansion (Phase II)



Proposed Expansion
(End of Grant Cycle)



The AVC submitted a grant proposal to expand their teletherapy services statewide particularly to infants born in 2019 and 2020. The AVC provides Listening and Spoken Language (LSL) services to children who are DHH. The AVC's LSL program goal is to ensure graduates of the program develop the communication and language skills needed to take advantage of general education programming without the need for special education services. This grant, if awarded, would allow the AVC to hire and train Speech Language Pathologists (SLP) and to certify them in LSL practices - delivering 9,000 LSL intervention services to 150 Children who are DHH regardless of geographic location or financial need. More information about this grant can be found in Appendix H.

Policy Driven and Other Improvement Opportunities

In addition to the legislative and grant funding opportunities above, there are two other areas identified which can improve rates of diagnosis in Georgia:

1. Expansion of CARES Act to privately enrolled children with disabilities
2. GaCDHH Multiagency Task Force Diagnostics Intensive

Expansion of Families of Children with Special Needs Reimbursement Program to Privately Enrolled Students

The [Families of Children with Special Needs Reimbursement Program](#) has designated ten million dollars to assist students in Georgia with the highest needs for expenses incurred due to school closings during the pandemic. Currently, these funds are restricted to children with IEPs who are also enrolled in public schools. Many children who are Deaf, Hard of Hearing or DeafBlind, as well as children with other disabilities, are enrolled in private schools and receive accommodations to ensure accessibility within these private settings. However, during the pandemic, remote learning has put these children at a specific disadvantage even if they were previously in a private and/or mainstream educational setting. In addition, many children who are DHH and enrolled in private schools have an official IEP even though they are not enrolled in a public school per se. The GaCDHH reached out to the Governor's Office of Budget and Planning to request an expansion to these students to privately enrolled students with special needs and this is currently under consideration.

GaCDHH Multiagency Taskforce – 12 Month Intensive on Diagnostics

Per OCGA § 30-1-5, a multiagency task force must convene regularly to establish collaboration between agencies and to ensure a seamless, integrated system of care from birth to literacy for children who are DHH. The GaCDHH recommends that this taskforce assemble as soon as possible to focus on ways to collaborate, share data and develop a child centric ecosystem with an exclusive focus on diagnostics over the next 12 months. While many agencies and private entities have separate efforts underway to improve the current state of follow up diagnostic testing, there must be frequent communication and collaboration to improve results and ensure efficiencies. Members of the taskforce are listed in Appendix B. Meetings should also include private and other agency providers of diagnostic services in the state to ensure comprehensive collaboration.

Thank you to Governor Kemp and Georgia's General Assembly

The Georgia Commission for the Deaf or Hard of Hearing (GaCDHH) sincerely thanks Governor Kemp and the General Assembly for the increased focus given to Deaf and Hard of Hearing children in the state over the past few years. A special thanks must be given to Chairman Penny Houston whose tireless efforts to support and advocate for DHH children in Georgia has resulted in multiple pieces of legislation, policy changes, public assistance programs and many other efforts to improve their outcomes.

This is an exciting time to be working for the future of Georgia's children who are DHH. The GaCDHH, the DPH, the DECAL, and the GaDOE thanks each of you for your time and commitment to Georgia's children who are DHH. The Commission's and the multiagency task force's aim is to develop a comprehensive and collaborative plan which will be put into action over the next twelve months if grant funds are awarded to improve access to teleaudiology across the state.

Appendix A: Appointees for the Georgia Commission for the Deaf or Hard of Hearing and Update (GaCDHH)

The GCDHH is comprised of 12 members, ten of whom are appointed by the governor. The Senate Committee on Assignments appoints one member, and the Speaker of the House of Representatives appoints the final member. The GCDHH serves as the principal agency of the state to advocate on behalf of persons who are DHH by working to ensure those persons have equal access to the services, programs, and opportunities available to others. The GCDHH assists children who are DHH and their parents in advocating for equal access to services, programs, and opportunities, advises the governor, General Assembly, Commissioner of Human Services, and the Commissioner of Community Health on the development of policies, programs, and services affecting people who are DHH and on the use of appropriate federal and state moneys for such purposes. Currently, six positions are available and the GaCDHH hopes to have them filled by October 2021.

Position	Appointed By	Current Commissioner
DHH adult – ASL	Governor	Jimmy Peterson
DHH adult – English	Governor	Jennifer Clark
DHH adult – English and ASL	Governor	Ellen Rolader
Deaf-Blind Adult	Governor	
Late deafened (after 18 years)	Governor	
Parent of DHH Child – English	Governor	Kelly Jenkins
Parent of DHH Child – ASL	Governor	Deshonda Washington
Otolaryngologist or Audiologist	Governor	
Private Provider of Services for DHH	Governor	
Person involved w/Programs for DHH	Governor	Dr. Amy Lederberg
At Large	Senate Committee on Assignments	
At Large	Speaker of the House	
Current Chairperson	GCDHH votes	Kelly Jenkins

Appendix B: Appointees for the Multiagency Task Force

Created within the GaCDHH is a multiagency task force for the purposes of establishing a system of collaborative governance responsible for:

- making recommendations to the General Assembly and the governor regarding essential improvements to the statewide system of developmental and educational services that support age appropriate language and on-grade-level literacy proficiency for children who are DHH from birth to third grade,
- engaging with stakeholders at the Department of Public Health (DPH), the Department of Early Care and Learning (DECAL), and the Georgia Department of Education (GaDOE) to ensure a seamless, integrated system of care from birth to literacy for children who are DHH, and
- developing and supporting interagency practices and policies that support the implementation of individualized birth to literacy plans for each child who is DHH.

Position	Current Representative
Chairperson of GaCDHH	Kelly Jenkins
Executive Director of Task Force	Dr. Stacey Tucci – GaDOE Language and Literacy Director
GaDOE – Direct authority over Deaf Education	Dr. Kenney Moore – Executive Director of GaDOE Division of State Schools
DPH – Direct authority over Early Intervention	LaToya Osmani – Division Director of the Division of Health Promotion Jeannine Galloway – Maternal and Child Health Section Director Tina Turner – Child Health Services Deputy Director Kimberlee Spencer – Deputy Director of Early Intervention
DECAL – Authority over Preschool Programs	Jennie Couture – Practice and Support Services Director
DPH – State EHDI Coordinator	Dr. Brandt Culpepper – Early Hearing Detection and Intervention Team Lead
DPH – The Division of Health Promotion – Direct Responsibility over Data Management	Michael Lo – EHDI Data Manager/Program Evaluator
GaDOE – Direct Responsibility over Data Management	Nicholas Handville – Chief Data and Privacy Officer
State Board of Education Member	Scott Sweeney – State Board of Education Chair
Georgia Technology Authority	Steve Nichols – Chief Technology Officer Nikhil Deshpande – Chief Digital Officer Cameron Fash – Director of Intergovernmental Relations

Appendix C: Appointees for Stakeholder Advisory Committee

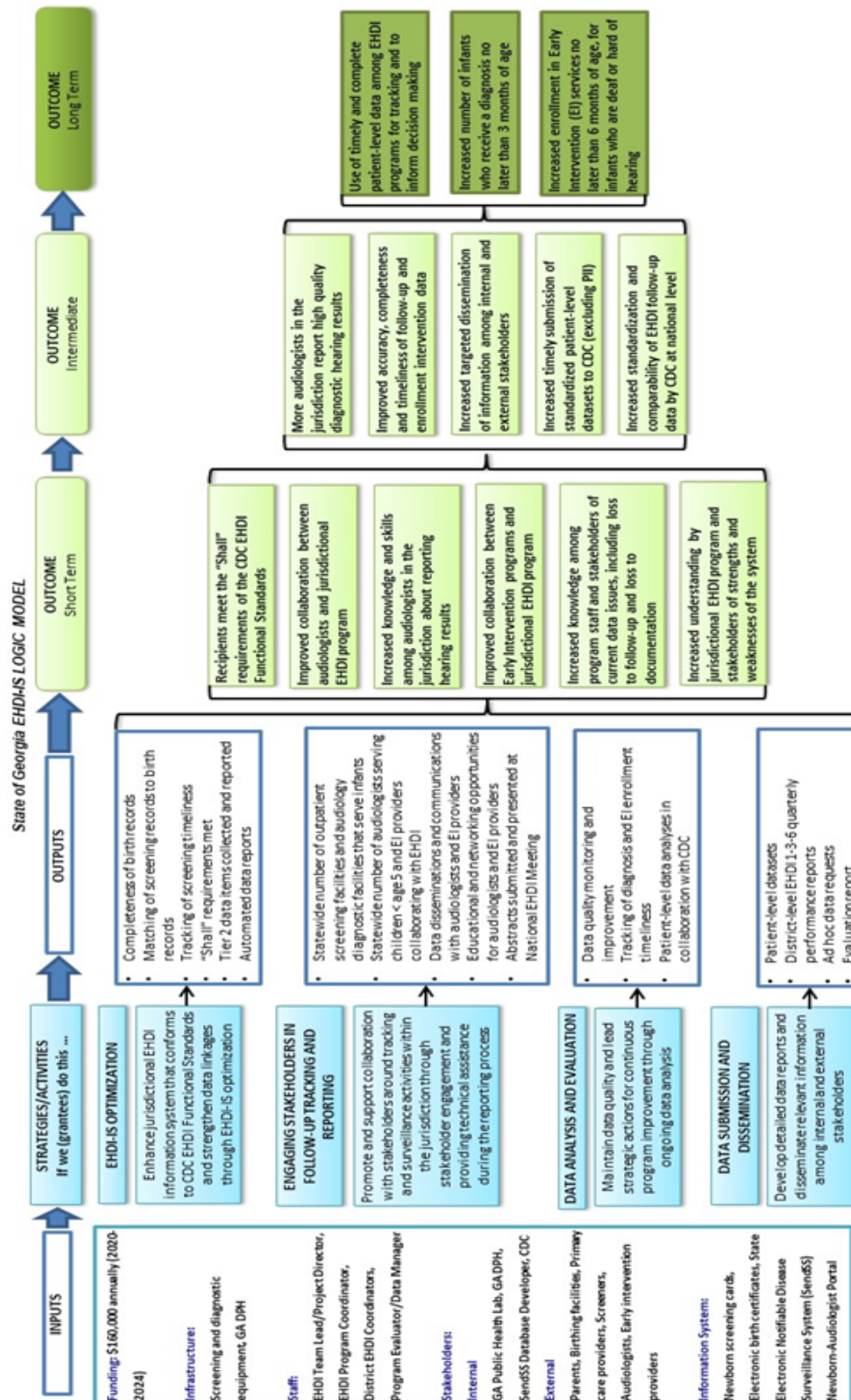
A stakeholder advisory committee was created to provide information and guidance to the multiagency task force regarding the following deliverables:

- (1) a list of developmental milestones necessary for progressing toward age appropriate language and English literacy proficiency by the end of third grade
- (2) a comprehensive and accurate web and print based resource for parents and professionals
- (3) a list of currently available assessments appropriate for evaluating an individual child's progress towards age appropriate language and English literacy proficiency
- (4) an individual report of a child's current functioning, developed in collaboration with professionals and the parents or caregivers, that will be used for the purpose of monitoring a child's progress toward age appropriate language and English literacy proficiency by the end of third grade

The stakeholder advisory committee is comprised of 13 members appointed by the GaCDHH based upon the following criteria for each member as described in the table below.

Position	Current Representative
Parent of DHH Child under 10 – ASL (child’s language)	Krystle Wilson
Parent of DHH Child under 10 – Spoken English (child’s language)	Katie Hope
Parent of DHH Child under 10 – English as second language (home language)	Lauren Sangaline
DHH Adult – ASL	Vyron Kinson
DHH Adult – Spoken English	Jonathan Brilling
Early Interventionist – ASL	Lisa Collis
Early Interventionist – Spoken English	Debbie Brilling
Early Interventionist – non-Metro Area	Dr. Heidi Evans
Teacher – Spoken English, non-Metro School	Kathy Lyons
Teacher – ASL and Spoken English	Cherie Wren
Deaf Teacher – ASL, State School for the Deaf	Wende Grass
Teacher – Spoken English, Metro School	Lesley Cauble
Pediatric Audiologist	Dr. Jill Maddox

Appendix D: EHDI Logic Model 2021 & Process Flow



Program Overview	<ul style="list-style-type: none"> Focuses on early identification of childhood hearing loss to provide early intervention services that promote language development. Consists of three key elements: initial hearing screening prior to hospital discharge and no later than 1 month of age, diagnostic hearing evaluation by 3 months of age (for those who fail the hearing screening in one or both ears), and early intervention by 6 months of age (for those diagnosed with permanent childhood hearing loss). Program partners with birthing facilities, audiological facilities, and early intervention programs for family coordination of services
Database / Data systems used	<ul style="list-style-type: none"> State Electronic Notifiable Disease Surveillance System (SendSS) Newborn module
Target Population	<ul style="list-style-type: none"> All Georgia occurrent births Children with diagnosed hearing loss up to the age of 5
Intended Outcomes	<ul style="list-style-type: none"> Promote language and literacy for infants and young children with permanent childhood hearing loss through care coordination and enrollment in appropriated early identification services
Time Frames for execution	<ul style="list-style-type: none"> EHDI "1-3-6" Benchmarks: Newborn hearing screening before 1 month Diagnostic evaluation before 3 months Early Intervention before 6 months of age
Audience for the process map	<ul style="list-style-type: none"> Birthing facilities Audiology Facilities Early Interventionists/Intervention Programs (Birthing facilities, Georgia PINES, Hands & Voices, Auditory Verbal Center, Audiology facilities, BCW, CMS, Children's 1st) Primary Care Providers Parents/Families ENT Physicians
Key Partners / Stakeholders	<ul style="list-style-type: none"> Birthing facilities Audiology Facilities Early Interventionists/Intervention Programs (Birthing facilities, Georgia PINES, Hands & Voices, Auditory Verbal Center, Audiology facilities, BCW, CMS, Children's 1st) Primary Care Providers Parents/Families ENT Physicians

LEGEND		NARRATIVE
ACRONYM	DESCRIPTION	
OAE	Otoacoustic Emissions	<p>This flow chart outlines key processes involved in Georgia's Early Hearing Detection and Intervention (EHDI) Program. The three key phases of the program, the EHDI 1-3-6 plan, includes all infants having a complete hearing screening before 1 month of age, those who fail the hearing screening for one or both ears receive a diagnostic hearing evaluation by 3 months of age, and those with diagnosed with permanent childhood hearing loss enrolled in early intervention by 6 months of age.</p> <p>Key partners that assist with the family coordination of EHDI services are additionally highlighted in this map.</p>
AUD	Audiology/Audiologist	
ABR	Automated Auditory Brainstem Response	
BCW	Babies Can't Wait	
C1st	Children's First	
ENT	Ear Nose and Throat	
EHDI	Early Hearing Detection and Intervention	
EI	Early Intervention	
Georgia PINES	Georgia Parent Infant Network for Educational Services	
MH	Medical Home	
NICU	Neonatal Intensive Care	
NB	Newborn	
PCP	Primary Care Provider	
RF	Risk Factors	
SendSS	State Electronic Notifiable Disease Surveillance System	
UNHSI	Universal Newborn Hearing Screening and Intervention	
W.B	Well Babies	



Appendix E: Overview of Georgia Mobile Audiology



Georgia Mobile Audiology is funded by the Georgia Legislature and the GA Department of Education, State Schools Division. It is charged with addressing the shortage of available pediatric audiology services to ensure that children with hearing loss in Georgia can reach their full potential in language and literacy.

Our goals for Georgia Mobile Audiology are to ensure that:

- Families have equal access to audiological services throughout the state
- Babies receive timely newborn hearing screening follow-up services
- The overall rate of children lost to follow-up goes down and does not disproportionately affect children in rural areas
- School-aged children receive timely ongoing care and management

FREQUENTLY ASKED QUESTIONS

WHO ARE SERVICES PROVIDED TO?

- Children birth to 22 years of age
- Children with lack of audiological care near their home, insurance barriers, risk factors for loss-to-followup
- Professionals who are interested in professional development

WHAT SERVICES ARE PROVIDED?

- Newborn hearing screening follow-up
- Diagnostic non-sedated Auditory Brainstem Response (ABR) evaluations
- Diagnostic behavioral testing
- Hearing aid management
- Family education
- Community outreach
- Care coordination

HOW DO I MAKE A REFERRAL?

Email us at MAPinfo@doe.k12.ga.us or fill out our [contact form](#)



NEED SERVICES?
REACH OUT
TO US!



INTERESTED IN LEARNING MORE?

Check out our website: www.GAmobileaudiology.org



Richard Woods, Georgia's School Superintendent | Georgia Department of Education | Educating Georgia's Future

Appendix F: Non-Compliance with OCGA § Data Issues and Delayed SendSS Reporting of Diagnosis

One aspect of EHDI that has been a challenge for many years is loss to documentation for infants receiving a follow-up diagnostic evaluation, but not reported to EHDI. Given the current data collection and data reporting procedures, it is extremely difficult to determine which infants did not receive a diagnostic evaluation at all and which infants received a diagnostic evaluation but were not reported as having an evaluation due to reporting noncompliance. To that end, EHDI focused on engaging audiologists providing EHDI follow-up services to report results as mandated by Georgia law through the SendSS database. In 2009, EHDI developed the web-based information system developed and maintained by DPH's Office of Information Technology that is integrated with other child health data systems within the SendSS-Newborn module. Audiologists are encouraged to report suspected or confirmed cases directly into the Audiology Portal in SendSS to facilitate and expedite data entry and referrals for EI and support services. Access to the audiology portal is role-based and allows users to view and modify information only in the EHDI module in SendSS. The audiology portal is used primarily by licensed Georgia audiologists, upon approval, and by state and district EHDI staff.

Again, Georgia's 159 counties are divided into 18 health districts with a designated EHDI coordinator in each district to facilitate follow-up and assist with care coordination for families of infants who do not pass the initial hearing screening as well as those diagnosed with hearing loss. In some districts, the District EHDI Coordinator hold dual roles in their district, serving as District EHDI Coordinators and serving roles for other MCH programs. Data captured in the audiology portal are matched to a child's unique record in SendSS based on key demographic variables. Data are stored in a back-end, SQL database table, allowing state EHDI staff to download from SendSS into an Excel spreadsheet for analysis. If there is no existing record in SendSS for a child being reported, the EHDI coordinator receives an automated notification to review the data submitted and upload information for a new child (e.g., a Georgia resident born in another state, a child who moved to Georgia from another state, etc.). EHDI obtained a Georgia Audiology Roster in January 2021 from the Georgia Licensure Board for Speech Language Pathology and Audiology. The roster lists 642 active audiologists in the state, with 498 of those on the list holding a Georgia address (SendSS users must be providing services in Georgia). Through licensure, all audiologists are eligible by law to provide follow-up services to infants and young children, although most licensed audiologists in Georgia do not provide services to infants and young children. Currently, there is no single list that designates who is providing audiological services to infants. EHDI state and district staff maintain a list of active facilities serving EHDI families. To promote engagement and reporting by audiologists, EHDI has conducted orientation sessions to audiologists new to Georgia and presented to more than 35 licensed audiologists who provide infant assessment services in Georgia and has collaborated with Georgia Mobile Audiology to promote the use of the SendSS Audiology portal. A user's guide, a data dictionary and a data management plan are available to staff to guide consistent utilization and interpretation of the data captured in the database.

As a result, the number of audiologists with active SendSS accounts for the audiology portal realized a 30% increase (85 to 110) over the past year. EHDI anticipates that the increased number of accounts will promote progress towards earlier identification of hearing loss in the state and a higher proportion of infants who do not pass their initial hearing screening being completed and reported before 3 months of age. Strategies to increase reporting also include collaborations with GMA, outreach sessions and updates presented at stakeholder meetings, and engaging audiologists as champions in their region to promote reporting.

Critical to the ability to measure progress are the improvements and enhancements to the EHDI module within the SendSS database through collaborations with the SendSS database programmer. In addition to the modifications mentioned above, changes also include automated notifications sent to district staff for infants

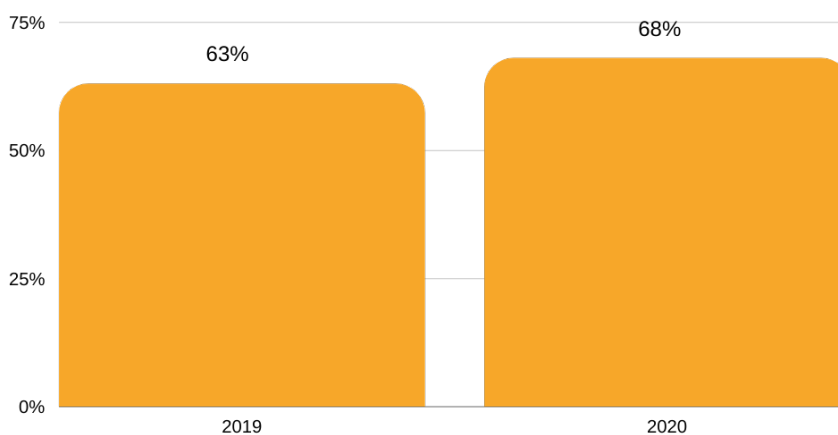
born at birthing centers or at home, automated follow-up reminders to refer infants with confirmed hearing loss to CMS, and the addition of a “parent refused” option for outpatient rescreen services. Changes to the audiology portal included the addition of categories to allow more flexibility in reporting diagnostic test results and the ability to designate follow-up services provided through teleaudiology. These modifications have increased efficiency in many areas, allowing staff to spend time on care coordination with families.

Audiologist Compliance with SENDSS Reporting within 7 Day Window
Drives Compliance Improvement



Source: GA DPH/EHDI Reporting to SENDSS as of 8-20-2021 for 2019 and 2020

Compliance with SENDSS Reporting within 7 Day Window
Has Improved



Source: GA DPH/EHDI Reporting to SENDSS as of 8-20-2021 for 2019 and 2020

Appendix G: Summary of Teleaudiology Grant Proposal GA-0008050

Proposal Name: Collaborative Rapid Scaling of Statewide Tele/Mobile Audiology Capacity to Improve Diagnosis of Hearing Loss Among Infants Missed during COVID-19

Problem Statement: Per OCGA § 31-1-30, all infants in Georgia must receive a Newborn Hearing Screening before discharge from the hospital. Most infants who fail this screening are not receiving follow-up diagnostic testing by 3 months of age per CDC guidelines¹. The COVID-19 pandemic has exacerbated this dilemma, and many more infants who may be DHH have not been identified and are not receiving timely EI. In 2019, only 19% of the infants who failed their newborn hearing screening were reported as having a diagnostic exam by 3 months of age². This is a rapid decline from 31% in 2017 and 23% in 2018 and directly influenced by the lack of services available during COVID-19 as many private practices restricted services, and parents were uncomfortable leaving the home for follow-up testing. Children who do not receive timely diagnostic testing and EI are unlikely to achieve age-appropriate language and on-grade-level literacy skills. This has an economic impact on the state as student literacy rates impact state expenditures (e.g., special education and social welfare costs) as well as a loss of income tax revenue (i.e., lack of employment opportunities) for this population.

Location: Statewide; targeting high risk populations.

Funds Requested: \$3,918, 268

Target Population: 3,300 infants born in 2019 and 2020 who failed their newborn hearing screening for which a follow-up diagnostic test is not recorded. Infants to be triaged by known risk factors such as rural location, household income, latency of diagnosis, maternal education, and race/ethnicity.

Project Goals and Activities: Three Georgia programs with proven success in providing diagnostic testing to infants via mobile and/or teleaudiology services are committed to collaborating to rapidly scale their diagnostic capabilities statewide to diagnose as many infants as possible.

- The Georgia Department of Education's Georgia Mobile Audiology program
- The University of Georgia's Speech and Hearing Clinic
- The Atlanta Speech School's Access to Language Parent Navigation program

Mobile Audiology "pods" will consist of a parent navigator/audiology technician, mobile diagnostic equipment and a licensed pediatric audiologist who can work onsite or remotely using teleaudiology to diagnose infants. These pods will move throughout the state to communities with the most infants in need of diagnostic testing utilizing public libraries and public health centers as testing facilities.

¹ <https://www.cdc.gov/ncbddd/hearingloss/2019-data/04-screen-by-one-month.html>

² <https://www.cdc.gov/ncbddd/hearingloss/screening.html>

Appendix H: Summary of Teletherapy Grant Proposal GA-0008447

Proposal Summary

Due to COVID-19, it is projected that Georgia has nearly 2,500 infants in need of follow-up audiological services including screening, diagnostic evaluations, and EI. These are children who were born in 2019 and 2020 who failed the newborn hearing screening but are not reported as having follow-up screening and diagnostic services due to COVID-19 related factors. This is presumably true for many children born in 2021 although data for these children are not yet available. Using Georgia's rate of incidence for pediatric hearing loss, it is estimated that over the next several years, 300-350 of the 2,500 children who were referred for follow-up audiological services in 2019 and 2020 will likely be diagnosed as DHH. The Georgia Department of Education's (GaDOE) State Schools Division has submitted a grant request to the Governor's Emergency Education Relief Fund II (GEER II) to implement an aggressive outreach strategy in collaboration with the Georgia Department of Public Health that identifies children in need of follow-up screenings and diagnostic evaluations and to make direct referrals for children eligible for immediate intervention services.

For families with children who are DHH and want to begin listening and spoken language (LSL) intervention promptly, AVC proposes to utilize GEER II funding to deliver LSL intervention services statewide via a tele-health model. A significant portion of the 2,500 Georgia infants who missed audiological services due to COVID-19 are now delayed in meeting best practice guidelines developed by the Centers for Disease Control (CDC). The CDC recommends all infants meet the 1-3-6 benchmarks (i.e., newborn hearing screening and rescreen by one month of age, diagnostic evaluation by 3 months of age, and enrollment into EI by 6 months of age). The earlier a DHH child can access LSL intervention the more likely the child can develop age-appropriate communication skills and transition into general education classrooms without the need for special education services.

Special education costs combined with medical costs and lost wages have a per person lifetime economic impact to Georgia taxpayers of approximately \$532,000¹⁶¹⁷¹⁸. The AVC can provide 2-5 years of LSL services per child for a cost of \$30,100-\$75,000. This intervention has been proven to virtually eliminate the need for special education services for children who are DHH. The cost per child for LSL is significantly lower than the cost per child for special education services.

AVC, Inc. requests \$914,967 over a 3-year period. Targeted communities include Children who are DHH throughout Georgia. The goals are to: 1) Increase the number of certified LSL specialists (ideally University of Georgia graduates) available to serve Children who are DHH across Georgia; 2) Provide sustainable LSL services to Children who are DHH across Georgia through a tele-health model.

Description of the Issue

Although Georgia has mandated newborn hearing screenings since 1999, gaps in the current system make it difficult to meet the current demand for services. There is an urgent need to address the families who experience significant barriers to service including families who are economically challenged (e.g., Medicaid recipients, uninsured, underinsured), families who live in rural/non-metro areas, and native Spanish speaking families. AVC will focus on serving families experiencing one or more of these barriers to care. Based on AVC's client demographics, 65% are insured by Medicaid, 10% are uninsured, and 25% are covered by private insurance but many are considered underinsured due to prohibitive annual deductibles. In addition, 33% of clients are native

¹⁶ <https://www.cdc.gov/ncbddd/hearingloss/screening.html>

¹⁷ Grosse SD. Education cost savings from early detection of hearing loss: New findings. *Volta Voices* 2007;14(6):38-40

¹⁸ [Economic Costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and Vision Impairment --- United States, 2003 \(cdc.gov\)](https://www.cdc.gov/economic-costs/)



Spanish speakers and require bilingual (i.e., Spoken Spanish and Spoken English) service providers. This project is intended to support families with DHH infants and children who were born during 2019 and 2020, who failed the newborn hearing screening but did not receive follow-up diagnostic services including immediate and effective implementation of tele-health language intervention services.

Teaching Children who are DHH to interpret sound helps them develop the cognitive skills needed for reading because our writing system is based on letters that represent sounds. Without these sounds, our phonics system is hard to learn and apply. The AVC's approach to teaching Children who are DHH listening and spoken language not only supports children's reading achievement, it is proven to also reduce the need for reading remediation that is necessary when pediatric hearing loss goes undetected. In fact, many Children who are DHH who do not receive aggressive language intervention during the early years of brain development do not achieve age-appropriate language. Language is a foundational skill for reading and Children who are DHH who do not achieve age-appropriate language often graduate functionally illiterate. The AVC's LSL program goal is to ensure graduates of the program develop the communication and language skills needed to take advantage of general education programming without the need for special education services.

Nine of every ten Children who are DHH are born to hearing parents who communicate using spoken language. Helping Children who are DHH learn to use listening and spoken language allows them to build connections with family members through shared language use and supports their inclusion in general education opportunities that can place them on equal footing with their typical hearing peers. Children who are DHH who achieve age-appropriate language and on-grade-level literacy are more likely to graduate high school, attend college, and become financially independent. Children who are DHH who are not able to attain these linguistic and academic outcomes are more likely to receive disability benefits (e.g., Supplemental Security Income - SSI) in their adult lives. Many DHH adults face employment challenges due to depressed reading levels and may experience social isolation due to communication challenges.

To assess and analyze the scope of Georgia's diagnosis dilemma as a result of COVID-19, we consulted publicly available CDC data from the 2017-19 CDC EHDI Hearing Screening & Follow-up Survey (HSFS) which tracks state performance as it relates to CDC 1-3-6 guidelines. The data reveals that nearly 2,500 infants failed the mandated newborn hearing screening during COVID-19 and did not receive follow-up. It is estimated that over the next three years, 300-350 of these children will be diagnosed as DHH and will need of immediate LSL services.

The CDC reports the lifetime educational cost of hearing loss to be estimated at \$115,600 per DHH child¹⁹. Multiply this figure times 350 children (\$40,460,000) and this is what the state of Georgia can expect to spend educating this cohort over the next decade. Exacerbating this issue is the fact that Georgia has approximately 10 certified LSL specialists in two programs serving the entire state. Combined, these two programs provide LSL services to an annual cohort of approximately 200 Children who are DHH. Georgia's LSL specialists currently have an average annual caseload of 20 clients; they can serve up to a maximum annual caseload of 25 clients. If the estimate of 350 Children who are DHH missed during COVID-19 is accurate, Georgia would need an additional 14 LSL specialists to serve the newly identified Children who are DHH (350 Children who are DHH/25 max caseload = 14 LSL providers). This GEER II funding would allow AVC to support the certification of 6 new LSL specialists meeting almost 50% of the state's additional demand due to missed care during COVID.

One factor contributing to the low number of LSL providers in Georgia is the high cost of training Speech Language Pathologists (SLP) to work in a clinical setting. Georgia's Medicaid legislation and private insurance

¹⁹ <https://www.cdc.gov/ncbddd/hearingloss/screening.html>



credentialing require newly graduating SLPs complete a 12-month clinical fellowship before they can begin billing for services rendered. These requirements mean that organizations must cover the salary and benefits costs for each new clinical fellow for the first twelve months of their employment. This is a prohibitive cost for many local providers. Additional requirements toward LSL certification are a master's degree in Speech Language Pathology, plus three years of supervised training. Within the past seven years, AVC has supported a total of six SLPs with clinical fellowships. AVC currently employs 6 certified LSL specialists. With GEER II funding, AVC could support another six clinical fellowships over the next three years resulting in an addition of 6 more certified LSL specialists added to the Georgia workforce.

If we seek to be responsible stewards of our state's economic resources, allocating GEER II funding towards the expansion of the LSL workforce will be key to a successful expansion of statewide telehealth language intervention services. This expansion will provide access for Children who are DHH across the state and will support their achievement of age-appropriate language and on-grade-level reading.

Appendix I: Glossary of Terms

1-3-6 EHDI Guidelines – National best practices/guidelines established by EHDI encouraging screening by one month of age, diagnosis of hearing loss by three months of age, and entry into EI services by six months of age.

504 Plan – The 504 Plan is a plan developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment.

AAA – American Academy of Audiology

AAP – American Academy of Pediatrics

ASL – American Sign Language

AtL – Access to Language (AtL) initiative at Grady Hospital

ASTra Program – Advocacy Support & Training (ASTra) Program – Program available through Georgia Hands and Voices which provides parents with training on educational law and how to effectively advocate for their child, an advocate to assist them with IEPs, IFSPs and transition services and additional services and supports as needed.

AtL – Access to Language

AVC – Auditory Verbal Center

BCW – Babies Can't Wait – Provides services to improve developmental potential of infants and toddlers birth to age 3, with developmental or chronic health conditions. Provided under the DPH.

BIBS – Babies Information and Billing Services – web based central repository of case management data on children enrolled in and served by BCW.

BVI – Blind - Visually Impaired

CACDS – Georgia's Cross Agency Child Data System (CACDS) aligns critical data from programs and services for children zero to five and their families. The purpose of the system, is to identify services gaps, create opportunities for analysis and research, and provide an integrated and aligned approach to demonstrate how the state is meeting the needs of its youngest learners. Data are sent to the system from four partners currently, three agencies and Head Start grantees across the state. All participating programs are represented by a Governance Committee that meets regularly to discuss priorities for Georgia's CACDS (www.gacacds.com).

CDC – Centers for Disease Control and Prevention

DHH – Deaf or Hard of Hearing - A student who is Deaf or Hard of Hearing is one who exhibits a hearing loss, whether permanent or fluctuating, that interferes with the acquisition or maintenance of auditory skills necessary for the normal development of speech, language, and academic achievement. [Refer to 34 CFR 300.7 (3), (5)]

DB – Deafblind

DECAL – The Department of Early Care and Learning – Also referred to as Bright from the Start, Georgia Department of Early Care and Learning is responsible for meeting the childcare and early education needs of Georgia's children and their families.



GaDOE – The Georgia Department of Education – Oversees all aspects of public education in the state. The GaDOE is also responsible for the education of Children who are DHH ages 3 - 22. Includes Atlanta Area School for the Deaf and Georgia School for the Deaf.

DPH – The Georgia Department of Public Health – Lead agency in preventing disease, injury, and disability; promoting health and well-being; and preparing for and responding to disasters from the health perspective. Includes Maternal and Child Health (MCH) which oversees newborn screening and Early Hearing Detection and Intervention (EHDI) which provide services for Children who are DHH birth to 3.

EHDI – Early Hearing Detection and Intervention – Provided under the DPH, EHDI maintains and supports the statewide screening and referral system. This includes screening for hearing loss in the birthing hospital; referral of those who do not pass the hospital screening for rescreening; diagnostic audiological evaluation as appropriate as well as linkage to appropriate intervention for those infants diagnosed with hearing loss.

EI – Early Intervention – The provision of services to infants and young children with developmental delays and disabilities and their families. May include speech therapy, physical therapy, and other types of services.

FERPA – The Family Educational Rights and Privacy Act of 1974 (FERPA) is a federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

Georgia Hands & Voices - A parent driven non-profit organization that provides peer to peer support to families of children who are Deaf or Hard of Hearing regardless of communication modality. Children are served from birth-21.

Georgia PINES – Georgia Parent Infant Network for Educational Services – EI program for families of children birth to three years with a diagnosed hearing loss and/or visual impairment. Georgia PINES' Sensory Kids Impaired – Home Intervention (SKI-HI) program provides weekly services for children who are DHH. Georgia PINES may serve children up to age 5. Children 4-5 years are small percentage of those served by Georgia PINES and typically occurs when a child is late enrolled to the program.

GaCDHH – Georgia Commission for the Deaf or Hard of Hearing – Created in 2007 to advocate for DHH persons, work with state and federal agencies to promote economic development for DHH persons and to recommend legislation to the governor and General Assembly.

GENED – General Education

Georgia Milestones English Language Arts (ELA) Assessment – A comprehensive, summative assessment program spanning grades 3 through high school which measures how well students have learned the knowledge and skills outlined in the state-adopted content standards in English Language Arts.

Georgia Pathway to Language and Literacy – A group of stakeholders founded Georgia Pathway in 2010 to advance the literacy proficiency of Georgia's children who are Deaf or Hard of Hearing (DHH).

GKIDS – Georgia Kindergarten Inventory of Developing Skills – A year-long, performance- based assessment used to provide teachers with information about the level of instructional support needed by individual students entering kindergarten and first grade. GKIDS data is recorded based on the school system's curriculum map or report card schedule. Individual student reports are generated at the end of the year based on the data the teacher has entered throughout the year.

GLRS – The Georgia Learning Resources System – Network of 18 regional programs that provide training/resources to personnel and parents of students with disabilities to support academic achievement and post-secondary success. Provided under the GaDOE.



GMA – Georgia Mobile Audiology

GTA – The Georgia Technology Authority – Manages delivery of IT infrastructure services to the 85 Executive Branch agencies.

GTID – Georgia Testing Identifier – A unique, unchangeable, random ten-digit number assigned on a permanent basis to each student enrolled in a publicly funded K-12 Georgia school or program.

Healthy People 2020 - Healthy People provides science-based, 10-year national objectives for improving the health of all Americans. For 3 decades, Healthy People has established benchmarks and monitored progress over time to encourage collaborations across communities and sectors, empower individuals toward making informed health decisions and ensure the impact of prevention activities. <https://www.healthypeople.gov>

HIPAA – Health Insurance Portability and Accountability Act of 1996 – is federal legislation that provides data privacy and security provisions for safeguarding medical information.

HRSA – Health Resources and Services Administration – The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary federal agency for improving health care to people who are geographically isolated, economically, or medically vulnerable.

IDEA – Individuals with Disabilities Education Act – Passed in 1975, IDEA proposes to provide free, appropriate public education (FAPE) to children with disabilities and to give parents a voice in their child’s education. Part C of IDEA is a federal program that assists states in providing EI services to infants and toddlers with disabilities from birth until age 3. Part B of IDEA governs how special education and related services are provided to school-age children ages 3-22.

IEP – Individualized Education Program – Framework for determining the meaning of the term a free, appropriate public education (FAPE) in the least restrictive environment (LRE), which is developed and reviewed annually and must be in effect at the beginning of each school year in accordance with IDEA (Individuals with Disabilities Education Act). This is an education document for children from three to 22 years of age.

IFSP – Individual Family Service Plan – Serves children birth to three years of age with a focus on family involvement. When a child moves from BCW to special education, the IFSP is replaced by an IEP.

INSITE – An EI program for children who are DHH, VI, or DB and who have additional disabilities and administrated through Georgia PINES.

JCIH - Joint Committee on Infant Hearing – National committee within the American Speech- Language-Hearing Association which addresses issues that are important to the early diagnosis, intervention, and follow-up care of infants and young children with hearing loss. Created the 1-3- 6 Guidelines.

LSLS – Listening and Spoken Language Specialist Certification – Awarded by the AG Bell Academy which is the global leader in Listening and Spoken Language Certification. The requirements for the Listening and Spoken Language Specialist (LSLS) Certification set universal professional standards for knowledge and practical experience providing listening and spoken language intervention for children who are DHH and their families.

MCH – Maternal and Child Health

NIH – National Institutes of Health

Part B Services – Provision of services for children with special needs from three years to 21 years as specified by IDEA.

Part C Services – Provision of services for children with special needs from birth through age two as specified by IDEA.

RESAs – Regional Educational Service Agencies – 16 agencies strategically located in service districts throughout the State of Georgia. The agencies were established for the purpose of sharing services designed to improve the effectiveness of the educational programs of the member school systems.

SendSS – State Electronic Notifiable Disease Surveillance System – the DPH’s information system for reporting screening, laboratory, and diagnostic results for notifiable diseases, including permanent hearing loss in children birth to five years of age.

SI – Sensory Impairment

SLDS – Statewide Longitudinal Data System (SLDS) - The Statewide Longitudinal Data System is designed to help districts, schools, and teachers make informed, data-driven decisions to improve student learning. SLDS is a free application that is accessed via a link in the district’s Student Information System (SIS). It provides districts, schools, and teachers with access to historical data, including Assessments, Attendance, Enrollment, Courses, and Grades beginning with the 2006-2007 school year.

SPED – Special Education

TWMB – Talk with Me Baby – A collaboration of six leadership organizations including the DPH, the GaDOE, and the Campaign for Grade Level Reading working to bring the concept of language nutrition into public awareness and to educate caregivers on the importance of talking with their baby every day. This program is not specific to Children who are DHH.

TDHH – Teacher of the Deaf/Hard of hearing

UNHS – Universal Newborn Hearing Screening – 1999 Georgia law requires that no fewer than 95% of all newborn infants born in hospitals in the state be screened for hearing loss at birth and that local birthing hospitals and audiologists must report data to DPH/EHDI when infants do not pass the initial hearing screen or are diagnosed with hearing loss.

VCSL – Visual Communication and Sign Language Checklist – A developmental checklist of visual (ASL) language development.

VI – Visually Impaired

VR – Vocational Rehabilitation - A set of services offered to individuals with mental or physical disabilities designed to enable them to attain skills, resources, attitudes, and expectations needed to gain employment.