

## Project Abstract

Early Hearing Detection and Intervention Program

Florida Department of Health

Division of Children's Medical Services

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Total Funds Requested: \$950,000 (\$245,000 Year 1, \$235,000 Remaining three years)

The purpose of the Early Hearing Detection and Intervention (EHDI) Program project is to develop a comprehensive and coordinated statewide EHDI system of care targeted towards ensuring that newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, and early intervention.

Of the 221,508 newborns born in Florida during calendar year 2017, 288 were **identified** with hearing loss after not passing the newborn hearing screening. Of those 288 infants, only 180 were identified timely, by three months of age. 283 of the 288 infants were **referred** for early intervention services timely, which is by six months of age. Failure to refer by the age of six months occurs because many infants are not diagnosed with a permanent hearing loss until after six months of age. The other reason is delays with reporting the confirmed hearing loss to the EHDI office by the diagnosing audiologist so that the early intervention referral can be made. Lastly, 167 of the 288 infants were **enrolled** in early intervention services. The most frequent reason for not enrolling in the early intervention program is a lack of response to letters and calls to the parent regarding initiating enrollment. The second most common reason is that the parents decline services. (All figures are as reported in the 2017 Centers for Disease Control and Prevention EHDI Hearing Screening & Follow-up Survey).

### Proposed services:

- Lead efforts to engage all EHDI system stakeholders within Florida to improve developmental outcomes for children who are deaf or hard of hearing (DHH).
- Provide a coordinated infrastructure to ensure: newborns are screened by one month of age, diagnosed by three months of age, and enrolled in early intervention by six months of age; and reduce loss to follow up/loss to documentation
- Identify ways to expand capacity to support hearing screening in young children up to three years of age.
- Strengthen capacity to provide family support and engage families with children who are DHH, as well as engaging adults who are DHH to mentor families of children who are DHH.
- Engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations, the need for hearing screening up to age three, the benefits of a family-centered medical home, and the importance of communicating accurate, up-to-date, evidence-based information to facilitate the decision-making process.
- Facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals and data sharing between the EHDI Program, and the Early Steps Program.

## Project Narrative

Florida Department of Health  
Division of Children’s Medical Services  
Early Hearing Detection and Intervention Program  
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## Introduction

The Early Hearing Detection and Intervention Program (EHDI) is housed within the Florida Department of Health, Division of Children's Medical Services, Bureau of Early Steps and Newborn Screening. The purpose of the EHDI Program is to develop a comprehensive and coordinated statewide EHDI system of care targeted towards ensuring that families with newborns, infants, and young children up to three years of age who are deaf or hard-of-hearing (DHH) receive appropriate and timely services including hearing screening, diagnosis, and early intervention (EI).

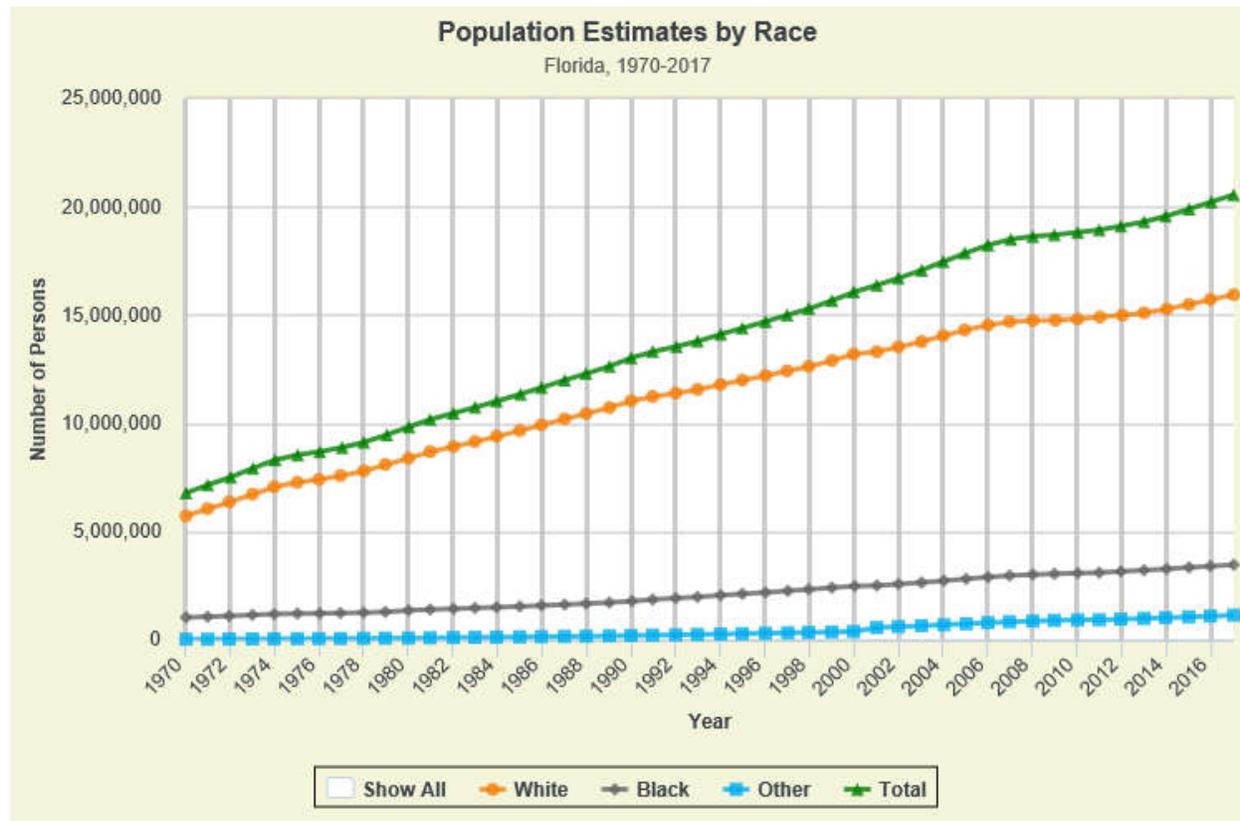
The major areas of focus for this project will be to 1) Lead efforts to engage all EHDI system stakeholders at the state/territory level to improve developmental outcomes of children who are DHH; 2) Provide a coordinated infrastructure to ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age; and reduce loss to follow-up/loss to documentation; 3) Identify ways to expand Florida's capacity to support hearing screening in young children up to three years of age; 4) Strengthen capacity to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI system; 5) Engage, educate, and train health professionals and service providers regarding the key aspects of the EHDI system; and 6) Facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and data sharing between the Florida EHDI Program and the Early Step Program, which is Florida's Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

Anticipated project outcomes include:

- Achieve and maintain at least a 95% screening rate of the number of infants that completed a newborn hearing screen no later than one month of age. Baseline data for 2017 is 90.66%.
- Achieve and maintain a minimum rate of 85% or increase, the number of infants that completed a diagnostic audiological evaluation no later than three months of age. Baseline data for 2017 is 77.82%.
- Achieve and maintain a minimum rate of 80%, the number of infants identified to be DHH that are enrolled in EI services no later than six months of age. Baseline data for 2017 is 73.65%.
- Increase by 20% from baseline the number of families enrolled in family-to-family support services by no later than six months of age. Data collected from Year 1 will be used as baseline data.
- Increase by 10% the number of families enrolled in DHH adult-to-family support services by no later than nine months of age. Data collected from Year 1 will be used as baseline data.
- Increase by 10% the number of health professionals and service providers trained on key aspects of the EHDI Program. Data collected from Year 1 will be used as baseline data.

## Needs Assessment

Florida is the third most populous state in the United States, with an estimated population of 21,299,325 in 2018 (U.S. Census). According to Vital Statistics, there were 221,508 live births in 2018. 98% of all births take place in birthing facilities, with 2% at home or in other facilities. Florida’s ethnic makeup is 25.7% Hispanic and 74.3 non-Hispanic. The population estimates for 2018 in relation to race was 77.39% white, 16.94% black, and 5.67% other.



The target population for this project is newborns, infants, and children under three years of age that are identified as deaf or hard of hearing and their families. These individuals are identified through the Newborn Hearing Screening Program. Newborn hearing screenings have been mandatory in Florida since 2000, per Section 383.145, Florida Statutes. All newborns born in a licensed birthing center that provides maternity and newborn care services in Florida must have a hearing screening prior to discharge or by one month of age, unless the parent objects in writing. Hearing screening results are reported to the Florida Department of Health on the Newborn Screening Specimen Collection Card, entered directly into an electronic reporting system, or faxed. All hearing screening results are stored in the same data system as the blood specimen results of the newborn screening. Vital Statistics records are uploaded daily into the newborn screening data system and records are matched between the two sets of data. The medical home physician on file is sent a laboratory report with newborn screening results, including the hearing screening, for each infant if the results were submitted via the Newborn Screening Specimen

Collection Card. All physicians have access to an online system to view newborn screening results.

Hearing screenings are conducted by a licensed audiologist, licensed physician, or appropriately supervised individual who has completed documented training specifically for newborn hearing screening. Medicaid and private insurance companies are to pay for the initial procedure for screening the hearing of the newborn or infant and any medically necessary follow-up reevaluations leading to diagnosis. Any person who is not covered through insurance and cannot afford the costs for testing is covered with safety net dollars which will provide the necessary testing free of charge.

If an infant does not pass the final inpatient newborn hearing screening, an outpatient rescreening is scheduled by the birthing facility or parent. A folder with information about the importance of rescreening is provided to all birth facilities to give to parents upon discharge. If the outpatient screening is not passed, a diagnostic audiological evaluation is scheduled by the facility where the second screening was failed or may be scheduled by the parent. Audiologists are expected to report evaluation results to the Newborn Screening Program office electronically or by faxing a Diagnostic Hearing Evaluation form within seven days of the appointment.

Much work has been done over the past 19 years to reach a consistent statewide hearing screening overall rate of 96% of the more than 220,000 annual births. Likewise, the lost to follow-up rate has reduced from over 30% to less than 10% of infants who did not pass the final inpatient newborn hearing screening. Follow-up efforts have included multiple letters and phone calls to parents. Letters are provided in English, Spanish, and Creole, and two follow-up staff members are fluent in Spanish. Interpreter services are also used to assist EHDI staff with phone calls to non-English speaking parents. Medical home physicians are sent multiple faxes and if an audiologist is known, this individual is called and faxed as well.

If a diagnosis of a permanent hearing loss is confirmed, a referral is to be made to the Early Steps Program's Local Early Steps (LES) office by the diagnosing audiologist within seven days of confirmation and by EHDI staff as a back-up within two business days of receipt. There are fifteen LES offices statewide, providing services in all Florida counties. EHDI staff sends a letter with a packet of information to families of each child under the age of three upon notification of the confirmed hearing loss diagnosis. Included in this packet, is information about the Early Steps Program, as well materials for the Florida School for the Deaf and Blind (FSDB) Parent Infant Program which is the designated family support organization that receives a portion of the EHDI funds to provide statewide parent support services.

An infant is considered eligible for Early Steps if a unilateral or bilateral hearing loss is present in the mild to profound range or if there is auditory dyssynchrony/auditory neuropathy. LES staff are to receive the referral and develop the Individualized Family Support Plan (IFSP) within 45 days of receipt of the referral. EHDI staff has read-only access to the Early Steps data system and uses this system to track the status of the referral and enrollment (IFSP) date for all infants referred by the EHDI Program. The family may decline early intervention services with Early Steps for any reason, before or after IFSP development. A child is not considered lost to follow-

up by Early Steps until at least three attempts are made to contact the family in two different modes of communication.

Services for each child are determined by that child's IFSP team which consists of the family, the Service Coordinator, and at least two professionals from different disciplines who have been or are currently involved in the assessment or provision of services to the child. IFSP meetings are arranged by the service coordinator and held at times and locations that are convenient to the family and in the native language of the family or other mode of communication used by the family, whenever feasible. The IFSP must contain information about the child's present development; the child and family outcomes, goals, and strategies; the specific services and their frequency, location, length, duration, and payment arrangements; the extent that services will be provided in the child's natural environment; medical or other supports needed or being received that are not required or funded under Early Steps; and a transition plan for once the child ages out of Early Steps at three years old.

The Florida EHDI Program collaborates with two advisory bodies. The Genetics and Newborn Screening Advisory Council (GNSAC) is mandated by Florida law, and provides advice to the Newborn Screening Program. It is comprised of 15 members, one of which is an audiologist. The other 14 members consist of consumers, four representatives from medical schools in Florida, the State Surgeon General or designee, a representative from Children's Medical Services or designee, the Agency for Persons with Disabilities Program Office representative, three practicing pediatricians (one of which must be a pediatric hematologist), a representative from the Florida Hospital Association, and an individual with experience in the Newborn Screening Program.

The Florida EHDI Program also works with the EHDI Advisory Committee to receive guidance on program activities. There are 12 participants on the EHDI Advisory Committee, and it is comprised of two parents of DHH children, one DHH individual, a representative from Florida Medicaid, the Florida School for the Deaf and Blind, the Department of Health, Office of Minority Health and Health Equity, Healthy Start, Early Steps, Leadership Education in Neurodevelopmental and Related Disabilities Program (LEND), a hearing screening organization, a birthing hospital, and Florida Hands and Voices (also a parent of a DHH child).

#### Progress with the 1-3-6 goals

Florida has made significant gains with the newborn hearing screening piece of the EHDI process; however, improvement is still needed within all parts of the EHDI system. In 2017, there were 223,579 occurrent births in the state of Florida. 95.76% of these newborns received a screening, and Florida had a 2.5% loss to follow-up/documentation rate for screening. 90.66% of the newborns in 2017 had a hearing screening by one month of age.

In 2017, 89.94% of infants received a diagnosis by three months of age, including typical-hearing and hearing loss. 77.82% of infants not passing the initial screening were diagnosed by three months of age. Florida's overall loss to follow-up/documentation for diagnosis was 9.39% in 2017.

57.98% of the infants diagnosed with hearing loss enrolled in Early Steps. 73.65% of the infants that enrolled with Early Steps, were enrolled by six months of age. In 2017, Florida had a 26.74% loss to follow-up rate for early intervention.

In 2017, 288 infants were identified with permanent hearing loss through universal newborn hearing screenings. Of those 288 infants, 180 were identified timely, by three months of age.

### Barriers

Some of the barriers for infants not being diagnosed by three months of age, referred by six months of age, and enrolled in early intervention services include:

1. Medical complications of the infant – Some medical conditions prevent the confirmation of a diagnosis of permanent hearing loss, the most common of which is middle ear dysfunction. This condition requires medical clearance before permanent hearing loss can be confirmed or ruled-out, thus delaying diagnosis. Another condition that delays the process is premature birth. The initial hearing screening is often delayed because it is recommended to be done prior to discharge which can be several months after birth for babies in the newborn intensive care unit (NICU). This delays the diagnostic testing which is needed to confirm the permanent hearing loss diagnosis.
2. Audiology appointment availability – Delays occur when audiologists have full schedules and appointments are scheduled later in the infant’s life. Currently, there are 377 known audiologists at 142 locations that serve infants in Florida.
3. No-shows/Cancellations – When parents do not show for appointments or cancel appointments, this further delays the process for diagnosis. This is especially problematic if the infant is close to three months of age when sedation is often required for testing, instead of natural sleep. When sedation is required, the rescheduled appointment occurs later due to the need for referrals, the length of the test, and the need for other specialists, such as an anesthesiologist.
4. Insurance Coverage - Parents often delay diagnostic appointments while waiting on health insurance coverage authorizations.
5. Delays with reporting the diagnosis – Diagnosing audiologists are expected to report the results of the evaluation to the Florida Newborn Screening Program within seven days of the appointment date, but there are delays with this occurring. Despite recommendations and training, many audiologists do not send information until prompted by EHDI Program staff.
6. No response to Early Steps’ attempt to contact – The most common reason a child is not enrolled in Early Steps is due to unsuccessful attempts to contact the family. Prior to considering the case lost to follow-up, Early Steps makes multiple attempts in different weeks by mail and phone. The parent contact information provided to Early Steps is the most recently obtained contact information provided by the diagnosing audiologist.

7. Parents decline Early Steps services – The second most common reason a child is not enrolled in Early Steps is due to the parent declining services prior to development of the IFSP. Early Steps contacts the family, usually by phone, and explains the process of obtaining services. The Service Coordinator meets with the family to obtain information necessary for development of the IFSP. A parent can decline early intervention services at any time and for any reason. Sometimes parents decline services with Early Steps because services will be obtained privately. Other times, the reason for the declination is unknown.

## Methodology

The Florida EHDI Program will lead efforts to engage and coordinate all stakeholders in the Florida EHDI system to meet the goals of this program by ensuring that newborns are screened by one month of age, diagnosed by three months of age, and enrolled in early intervention by six months of age. This will be accomplished through the following goals and objectives and related activities:

**Goal 1: Children who are DHH are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social, and emotional development.**

Objective 1.1: Achieve at least a 95% screening rate, for the number of infants that completed a newborn hearing screen no later than one month of age, by March 31, 2024.

Baseline data for 2017: 90.66% of newborns had a hearing screening by one month of age. Formula for calculating the measure:  $(\# \text{ Total Screened Before 1 Month of Age} / \# \text{ Total Screened}) * 100$ .

Florida will continue to analyze hospital data and request hospitals review and respond to their monthly and bi-annual reports to ensure accurate reporting is completed to the EHDI-IS. Additionally, Florida EHDI will provide technical assistance and training for all hospital or birthing center providers that have a not-screened rate of more than 4%, and an outpatient referral rate over 4%.

Objective 1.2: By March 31, 2024, achieve a minimum rate of 85% of infants that completed a diagnostic audiological evaluation no later than three months of age.

Baseline data for 2017: 77.82% of infants not passing the screen, were diagnosed by three months of age. Formula for calculating the measure:  $(\# \text{ Total Diagnosed Before Three Months of Age} / \# \text{ Total Not Pass}) * 100$ .

Florida EHDI will continue to analyze diagnostic data and implement quarterly reports of pending cases that are awaiting a diagnosis or reporting results to audiologists to ensure accurate reporting is submitted to the EHDI-IS. Additionally, Florida EHDI will provide technical assistance to medical home providers and audiologists on the importance of diagnosing hearing loss by three months of age. Electronic reporting will also be encouraged.

Objective 1.3: By March 31, 2024, increase by 15% from the 2017 baseline of 57.98%, the number of infants identified to be DHH that are enrolled in EI services no later than six months of age.

2017 Baseline data: 57.98% of the infants diagnosed with hearing loss enrolled in Early Steps. Formula for calculating the measure:  $\# \text{ Total Enrolled in EI before six months of age (Part C and Non-Part C)} / \# \text{ Total Enrolled in EI (Part C and Non-Part C)} * 100$ . Therefore, the objective is to increase the percentage of infants enrolled in EI by six months of age to 66.68% by the end of the project period.

To accomplish this objective, Florida EHDI will collaborate with the EHDI Advisory Committee to problem solve reporting challenges with Part C and Non-Part C early intervention enrollment. Work with the Early Steps State Office to implement local program reports or a method to follow-up on babies that are referred but not enrolled in Part C by the end of Year 1. And develop new partnerships with hearing aid dispensaries and cochlear implant centers to implement a data reporting process related to amplification and non-Part C EI.

**Goal 2: Lead efforts to engage and coordinate all stakeholders in the Florida EHDI System.**

Objective 2.1: Maintain or reduce loss to follow-up/documentation.

Baseline data for 2017: The overall percent loss to follow-up/documentation for diagnosis is 9.39%. Formula for calculating the measure:  $\# \text{ Contacted but Unresponsive} + \# \text{ Unable to Contact} + \# \text{ Unknown} / \# \text{ Total Not Pass} * 100$ .

Florida EHDI will continue to follow-up with parents, audiologists, and medical home health care professionals regarding the status of each newborn who needs diagnostic testing by 3 months of age. In addition, Florida EHDI will continue to partner with Vital Statistics, the Newborn Screening Follow-Up Program, and Florida Medicaid to share data and allow the EHDI Program to gain critical demographic information needed for follow-up.

Objective 2.2: By March 31, 2022, Florida EHDI will develop a state plan to expand infrastructure, including data collection and reporting, for hearing screenings for children up to age three.

The plan will use a public health approach that aligns with other public health programs, and will outline the resources, key stakeholders, partnerships, and services necessary to implement the plan.

Objective 2.3: Establish and maintain partnerships related to referral, training, and information sharing with various state stakeholders and programs.

Florida will maintain partnerships with Early Steps and the FSDB regarding referrals for children that are diagnosed with hearing loss and need early intervention. Florida will provide training and technical assistance with birthing facilities, medical home providers, audiologists, otolaryngologists, and early intervention providers. Florida will also exhibit at professional conferences such as the Florida Chapter of the American Academy of Pediatrics conference and

the Florida Academy of Audiologists. Florida will maintain partnerships with Vital Statistics, the Newborn Screening Follow-Up Program, Florida Medicaid, Early Steps, Birthing Facilities, Audiologists, and Medical Home Providers. Additionally, Florida EHDI will develop new partnerships with statewide cochlear implant centers, hearing aid dispensaries, and the Early Head Start Program. Florida will also complete an annual assessment of current partnerships and identify key partners who could help address gaps in the EHDI system.

Objective 2.4: Address diversity and inclusion within the EHDI System.

Florida EHDI will work with the EHDI Advisory Committee and the Department of Health Office of Minority Health and Health Equity to develop a plan to address diversity and inclusion to ensure that the EHDI system activities are inclusive of and address the needs of the populations it serves including geography, race, ethnicity, disability, gender, sexual orientation, family structure, and socio-economic status.

Objective 2.5: Develop and implement quality improvement strategies to monitor and assess program performance.

Florida EHDI will work with the EHDI Advisory Committee and the Quality Improvement (QI) Liaison with the EHDI Technical Resource Center Awardee to develop and implement new quality improvement strategies related to the following subjects:

1. Early Intervention referral and/or enrollment
2. Family engagement and family support

Objective 2.6: Develop, maintain, and promote a Florida specific website as a resource for families of children with hearing loss.

Florida EHDI will collaborate with FSDB, the designated parent support organization, to develop, maintain, and promote a website or webpage for the state that is user-friendly with accessible, culturally appropriate information for families and professionals that is accurate, comprehensive, up-to-date, and evidence-based, as appropriate to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communication modalities, as appropriate.

### **Goal 3: Engage, educate, and train health professionals and service providers in the EHDI system**

Objective 3.1: Educate providers on Florida-specific EHDI information.

Florida will collaborate with the three universities in Florida offering audiology programs, and work to educate students on the EHDI mission.

Objective 3.2: Educate stakeholders on the benefits of a patient/family-centered medical home and family engagement in the care of a DHH child.

Engage medical home providers by submitting abstracts to speak at and by exhibiting at state professional conferences.

Objective 3.3: Train providers on the 1-3-6 recommendations and the importance of timely screening, diagnosis, referral, and enrollment into EI services, as well as the need for hearing screening up to age three.

Florida will develop educational materials to be included in a welcome package sent to newly licensed audiologists and medical home providers.

Objective 3.4: Educate providers on the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communications modalities, as appropriate.

Collaborate with FSDB, the designated parent support organization, to develop educational training for early intervention providers regarding EHDI and the importance of early diagnosis and intervention, and best practices for working with families of children that are deaf and hard of hearing.

Objective 3.5: Collaborate with the LEND Program to update screening and diagnostic guidelines for providers.

Florida EHDI will partner with LEND Program to update Florida's screening and diagnostic guidelines for providers.

**Goal 4: Strengthen the capacity to provide family support and engage families with children who are DHH as well as adults who are DHH throughout the EHDI System.**

Objective 4.1: Engage families throughout all aspects of the project, involving family partners in the development, implementation, and evaluation of the EHDI Program.

Florida EHDI will collaborate with FSDB to identify family leaders willing to participate on a DHH family focused work group to advise the Program on ways to engage families throughout all aspects of the project.

Objective 4.2: Conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI system and collaborate with various leaders and policy makers in addressing the challenges to and providing solutions for the EHDI system.

Objective 4.3: Facilitate partnerships among families, health care professionals, and service providers to ensure that providers understand the best strategies to engage families.

Based on the ideas and recommendations determined by the DHH family work group, and EHDI Advisory Committee, the EHDI Program will conduct outreach and education to inform families of opportunities for involvement.

Objective 4.4: Use 25% of funding for family engagement and family support activities.

The contract with FSDB, will be renewed and will continue to be the recipient of this funding for family engagement and support activities.

Objective 4.5: Consult with the HRSA-20-051 recipient, the Family Leadership in Language and Learning (FL3 Center) for resources, technical assistance, training, education, QI and evaluation to strengthen the infrastructure and capacity for family engagement and family support in the state/territory.

Florida EHDI will participate in all applicable trainings, education and resource activities available from the FL3 Center, and include collaboration with this entity as part of the parent support contract.

**Goal 5: Facilitate improved coordination of care and services for families and children who are DHH through the development of mechanisms for formal communication, training, referrals and/or data sharing between the state/territory EHDI Program and early childhood programs including the IDEA Part C program.**

Objective 5.1: Assess the status of coordination across early childhood programs and develop a plan to improve coordination and care services through a variety of mechanisms based on the current level of integration across programs including early childhood programs.

Florida EHDI will demonstrate evidence of planning and stakeholder engagement through the development of a written plan.

### **Project Sustainability**

If grant funds were no longer available, the Florida EHDI Program would seek additional funding from within the state government to continue the EHDI project. Not all activities may be able to be funded in this instance, however, the EHDI Program would prioritize the activities most impactful for achieving the 1-3-6 goals.

### **Optional Needs Assessment Project**

Please see Attachments 7-9 for detailed information regarding this expanded project proposal.

### **Work Plan**

Please see Attachment 1 for a detailed account of program activities that will drive the project to meet the objectives and goals. The work plan also includes the proposed time lines, the staff members responsible for each activity, the stakeholders that will be involved, and collaborations with other federal and HRSA-EHDI-related projects.

### **Resolution of Challenges**

As the third most populous state, follow-up continues to pose a considerable challenge based on the volume of babies that are born and refer on the hearing screening in Florida. Increasing technical assistance and training to the hospitals regarding submission of all screening results, not just the initial screening results, may help to reduce some of the volume of cases that are opened due to a referred hearing screening.

Expanding the infrastructure for the data collection of children up to age three, will present some barriers. While the electronic reporting system for screenings does not have an age limit, babies born outside of the state of Florida are not currently able to be reported via this system, as it

utilizes the newborn screening blood specimens. Additionally, data sharing between agencies such as Early Head Start, or other entities providing hearing screenings outside of the newborn screening may be a significant obstacle. EHDI Program staff, the EHDI Advisory Committee, the EHDI-IS vendor, and other stakeholders will need to collaborate to address these challenges.

## **Evaluation and Technical Support Capacity**

Program performance evaluation will be monitored using the measures in the goals and objectives section below. The EHDI Coordinator will assemble an evaluation team, that will meet quarterly to discuss evaluation of the program as well as quality improvement projects. This team will be composed of the EHDI Coordinator, Data Analyst, the Hospital Hearing Coordinator, the Diagnostic Evaluation Coordinator, and a Follow-up Coordinator, to monitor the progress of these objectives, and to implement Plan-Do-Study-Act quality initiatives to improve performance on the goals and objectives. This team will also participate in discussions with the QI Advisor assigned through the EHDI National Technical Resource Center. Targeted technical assistance for lower reporting hospitals and audiologists will be determined as a part of this team's evaluation process, and improvement will be closely monitored each quarter.

### Measures

The following measures will be used to assess performance and progress toward the objectives of this project.

1. The percentage of newborns screened by one month of age will increase by 1.20% annually from the 2017 baseline of 90.66%.

This performance data is tracked using a report within the EHDI-IS. The numerator is the number of infants screened by one month of age, and the denominator is the total number of occurrent births. Individual hospital reports are sent on a monthly basis to hospitals for review and respond, to resolve as many non-reported or mis-reported results as possible. This data will be reviewed both from the initial reporting month, to three months after the reporting month, to analyze whether updates were made as a result of the report. This will assist the hospital hearing coordinator with monitoring hospital performance and assist the Evaluation Team to monitor trends for the hospitals and determine if technical assistance is needed.

2. The percentage of infants diagnosed by three months of age will increase by 1.80% annually from the 2017 baseline of 77.82%.

This performance data is tracked using the date of the appointment in which the infant was identified in comparison with the infant's date of birth. The date of the appointment is collected from the "Appointment Date" field in the electronic system or faxed form. The date of birth is obtained from the blood specimen card. Any discrepancies with the date of birth written on the evaluation form are resolved by comparing information with the infant's Vital Statistics record, which is linked to the patient's newborn screening record. When determining a percentage, the numerator is the number of infants who were identified by three months of age and the denominator is the number of infants identified.

Reports to determine the numerator and denominator are run for a date of birth range of one calendar year. The data for this measure is maintained within the EHDI-IS.

3. The percentage of infants enrolled in early intervention by six months of age will increase by 1.59% annually from the 2017 baseline of 73.65%.

This performance data is tracked using the date of the IFSP in comparison with the infant's date of birth. EHDI staff research each infant in the Early Steps data system on a monthly basis to determine if there is an IFSP in place or if the child has been closed to the program. If there is no IFSP date and the child has been closed, this child is considered not enrolled and is recorded on the previously mentioned file. If there is an IFSP date in the Early Steps data system, this date is recorded on the same file. The date of birth is obtained as described above. When determining a percentage, the numerator is the number of infants who had an IFSP in place by six months of age and the denominator is the number of infants identified. Reports to determine the numerator and measure are recorded on an Excel file.

4. The percentage of families enrolled in family-to-family support services by no later than six months of age will increase by 6.67% annually from the Year 1 baseline.

This information will be collected by the designated family support organization, FSDB, and will be provided to the EHDI Program. FSDB sends a monthly report to the EHDI Program which reports the number of families receiving family-to-family services, including those that are newly diagnosed and under the age of six months.

5. The percentage of families enrolled in DHH adult-to-family support services by no later than nine months of age, will increase by 3.33% annually from the Year 1 baseline.

This information will be collected by the designated family support organization, FSDB, and will be provided to the EHDI Program. FSDB sends a monthly report to the EHDI Program which reports the number of families receiving DHH adult-to-family services, including those that are newly diagnosed and under the age of nine months.

6. The percentage of health professionals and service providers trained on key aspects of the EHDI Program will increase by 10% from the baseline of 50 providers trained.

All providers that receive technical assistance or training are tracked including the type of assistance received, the date of the training, location, and the names of the individuals trained.

## **Organizational Information**

The Florida Department of Health, CMS, is well-equipped to continue to administer grants for the statewide implementation of EHDI. CMS is responsible for identifying, coordinating, and providing health and related services to children with special health care needs in Florida and is responsible for statewide administration of various state and federal programs for children from

birth to twenty-one. CMS is also the designated lead agency for implementation of the IDEA, Part C Program.

The Florida EHDI Program is an integrated part of the newborn screening and early intervention program statewide. The mission of the Florida Department of Health is to protect, promote and improve the health of all people in Florida through integrated state, county, and community efforts. The EDHI Program exists within the Florida Department of Health, CMS. There are seven full-time staff, and two part-time staff members, dedicated to the EHDI. See Attachment 5 –Project Organizational Chart.

The Florida EHDI-IS is the Newborn Screening data system which is used for follow-up for disorders detected through the patient's blood specimen, hearing loss, and Critical Congenital Heart Disease. The data system vendor is PerkinElmer, Inc. Vital Statistics matching occurs which enables program staff to query and analyze patient-specific demographics data according to the patient's birth certificate data, such as mother's educational level, mother's race, mother's ethnicity, and mother's age which are not collected on the blood specimen card.

Florida Department of Health has managed both the HRSA grant and CDC cooperative agreement since 2001. Individuals dedicated solely to the EHDI Program include:

- 1.) Public Health Services Manager, Jessica Meyer;
- 2.) Human Services Program Specialist, Margaret Waterman;
- 3.) Human Services Program Specialist, Felicia Clowers;
- 4.) Human Services Program Analyst, Harriet Hinson-Charlton;
- 5.) Human Services Program Analyst, Jatarra Bradley;
- 6.) Human Services Program Analyst, Ericka Horne;
- 7.) Human Services Program Analyst (Part-Time), Miranda Nerland;
- 8.) Health Data Analyst, Nikema Peterson; and
- 9.) Human Services Program Specialist (Part-Time), Vacant.

Jessica Meyer has been Florida's EHDI Coordinator for almost three years. Mrs. Meyer has a Master of Social Work degree, and prior to joining the Department of Health in 2017, she was responsible for program management, policy, quality improvement, contract management, training, and technical assistance for over five years with the Department of Elder Affairs.

Margaret Waterman has been with the EHDI Program for almost one year. Mrs. Waterman provides training and technical assistance to hospitals, audiologists, physicians, and midwives. Mrs. Waterman worked as a newborn hearing screening technician, and program coordinator with responsibilities for training other newborn hearing screeners in numerous large birth facilities for 12 years prior. Mrs. Waterman has a Master of Education degree, which provides her with expertise to use her first-hand experience to provide quality technical assistance and training statewide.

Felicia Clowers has worked with the EHDI Program for three years, with current duties related to follow-up to obtain diagnostic results, tracking the diagnostic data, and making referrals to Early Steps. She was originally hired to conduct follow-up of screening results due to her experience with handling parent calls and creating reports with her previous employer. She was promoted in 2019 to her current position.

Harriet Hinson-Charlton and Jatarra Bradley have been with the EHDI Program for two years. Mrs. Hinson-Charlton and Ms. Bradley's current duties are related to follow-up with families and health care professionals for newborns that did not pass the newborn screening.

Ericka Horne is new to the EHDI Program, and just started in October 2019. Ms. Horne recently graduated with a Master of Public Health degree, she is fluent in Spanish, and has patient and family care experience from working in the local pediatric emergency room. Her experience and skills are a welcome addition to the Program.

Nikema Peterson has been with the EHDI Program for almost three years as the EHDI Data Analyst. Ms. Peterson has a Master of Public Health degree and is currently enrolled in a PhD in Pharmacology. Her primary duties are interpreting data and ensuring data quality. Ms. Peterson is also responsible for developing and implementing data analyses, ensuring Vital Statistics data is maintained within the system, and other strategies that optimize statistical efficiency and quality.

Miranda Nerland works part-time for EHDI Program as a parent consultant. Her primary responsibility is to assist families and parents of children that are newly diagnosed as deaf or hard of hearing. Miranda's daughter is deaf and has other special healthcare needs. Miranda is a strong advocate for families and has received training through SKI-HI.

The EHDI personnel within the Newborn Hearing Screening Unit are under the direct supervision of Jessica Meyer, who is supervised by Marcy Hajdukiewicz, Chief of the Early Steps and Newborn Screening Bureau. Mrs. Hajdukiewicz oversees the Part C and newborn screening follow-up activities within CMS. The Division Director, Cassandra Pasley, J.D., B.S.N., oversees the Division of Children's Medical Services and directly supervises Mrs. Hajdukiewicz and the Bureau of Early Steps and Newborn Screening, as well as the Bureau of Child Protection and Special Technologies. Refer to Attachment 2 for job descriptions of key employees and Attachment 3 for biographical sketches of key personnel.