INTRODUCTION:

The overall goal of the Technological Enhancements to meet Societal Advancements (TESA) Project is to maintain and develop additional programming to support a comprehensive Virginia Early Hearing Detection and Intervention (VA EHDI) program by collaborating with key agencies and stakeholders to ensure timely follow-up and appropriate services for Virginia's children. The focus of the project will be to: 1) Lead efforts to engage and coordinate all stakeholders in the EHDI system to meet the goals of the program; 2) Educate and train health professionals and service providers in the EHDI program; and 3) Strengthen capacity to provide family support, and engage families with children who are deaf or hard of hearing (D/HH) in the EHDI system. The project objectives include:

- Utilizing learning communities to increase stakeholder engagement in EHDI systems;
- Supporting infrastructure that ensures 1-3-6 guidelines and reduces loss to follow up and loss to documentation, while utilizing technological enhancements;
- Expanding infrastructure to support hearing screening and promote the importance of continual screening, and diagnosis for children up to 36 months. Maintaining and improving partnerships for information sharing, referral and training;
- Conducting EHDI Advisory Committee (AC) meetings to engage stakeholders and incorporating them in QI strategies to meet EHDI system goals;
- Conducting outreach and educational trainings for healthcare professionals and service providers;
- Developing and maintaining active family engagement and leadership efforts for families of children identified through newborn screening, and provide programmatic and fiscal support for family leadership and engagement.

NEEDS ASSESSMENT:

Using Quality Improvement (QI) methods, VA EHDI has made improvements in screening rates, as well as ensuring all children diagnosed with hearing loss are referred to EI services. However, there is a need for improvement in timely diagnosing in accordance to the national 1-3-6 Guidelines. There have been minimal changes in loss to follow-up rates at diagnosis from 26.0 percent in 2016 to 25.7 percent in 2017. As a result, VA EHDI recognizes the need to identify the children who are at high risk for loss to follow-up, in order to make appropriate systematic changes. VA EHDI acknowledges the need for program enhancements to address societal advancements, and reduce gaps in the follow-up process.

Screening:

In 2017, 99,444 live births occurred in the Commonwealth of Virginia, of which, 97,692 (98.2 percent) were documented as completing the screening process. Loss to follow-up at the screening stage has continued to improve in recent years. In 2017, the loss to follow-up at screening was 3.4 percent. The average number of days to get a rescreen from January 2018 to August 2018 was 32.4 days, which decreased to 21.9 days from September 2018 to March 2019. VA EHDI attributes this improvement to a few specific measures implemented over the past few years. These include: 1) Continued integration of EHDI data with Electronic Birth Certificate (EBC) registry data; 2) Increased reporting from out of hospital birthing centers; 3) Targeted follow-up activities; 4) Prenatal education of newborn hearing screening by Home Visiting (HV) and Women, Infants, and Children (WIC) programs; and 5) Social media & public awareness campaigns.

VA EHDI recognizes that screening children who are born outside the hospital continues to be of concern. In 2016, 1,314 children were born outside of the hospital. Out of this population, 323 children were born with a midwife at a birthing center, of which 297 (91.9 percent) were documented as not having completed an initial hearing screening. This group is less likely to take their child for hearing screening after birth, to avoid unnecessary medical intervention. VA EHDI recognizes the need for system enhancements to capture hearing screening status for children born outside of the hospital.

Additionally, VA EHDI began outreach to midwives to capture children in need of a hearing screening. VA EHDI conducted site visits to birthing centers in 2017, to increase reporting of children born outside of the hospital, and to provide thorough follow-up and recommendations for timely screening. VA EHDI recognizes the need to accurately capture children born outside the hospital in the Virginia Infant Screening Infant Tracking System (VISITS). VISITS is linked with the EBC registry; however, there is a delay in capturing children born outside of the hospital. Currently, out-of-hospital birthing facilities submit birth certificates via paper forms, rather than reporting them in EBC. VA EHDI will collaborate with Vital Records to assist out-of-hospital birthing facilities in gaining access to Virginia Vital Events Screening and Tracking System (VVESTS), to allow them to be easily linked to VISITS to report hearing screening.

Only a few midwives and/or home birthing centers have the capability to conduct hearing screenings, leaving a large portion of children without an initial hearing screening shortly after birth. VA EHDI has maintained a high rate of completion of screening for children born at birthing hospitals and strives to ensure that all children complete the screening process by one month of age, regardless of where they are born.

Children at Risk for developing hearing loss:
VA EHDI collects data on children who are at risk for developing delayed onset hearing loss. In 2016, there were 6,961 children who passed their initial hearing screening with risk, and the number increased to 7,203 in 2017. In 2017, 38 children (0.5 percent) who passed with risk at their initial hearing screening were later identified with a hearing loss. In 2016, there were 457 children who failed their initial hearing screening with risk, and the number increased to 492 in 2017. In 2017, 71 children (14.4 percent) who failed with risk at their initial screening were later identified with a hearing loss.

In 2017, VA EHDI found that there were approximately 12 birthing hospitals who were not reporting any or very few children with risk indicators. VA EHDI recognizes the need for further training on identifying children who are at risk for developing delayed onset of hearing loss. Due to inadequate or lack of communication at the hospital, many families are unaware of their child's specific risk indicators. VA EHDI is exploring options to educate hospital screeners on the importance of identifying the risk indicators and reporting them. VA EHDI will consider the feasibility of creating informational resources for parents whose children are at risk for developing hearing loss. Additionally, in 2017, there were 1,273 (18.3 percent) children who passed the initial screening with risk, and did not have a Primary Care Provider (PCP) listed in VISITS. VA EHDI will determine a means to increase identification of PCPs for children who are at risk, to encourage appropriate and timely follow up.

Primary Care Provider (PCP):
In order to provide effective follow-up, it is important to identify the child's outpatient primary care provider at birth. In 2015, 937 children who failed or missed their newborn hearing screen in the hospital did not have a PCP listed in VISITS. This number decreased to 386 in 2017. This decrease is associated with the connection developed between VISITS and Virginia Immunization Information System (VIIS) in 2014, to improve the continuity of care for patients. The majority of physicians enter immunization information into VIIS. Due to the linkage, physicians have access to their patient's hearing screening results and can provide appropriate follow-up recommendations. Although the connection between VIIS and VISITS has been established, VA EHDI recognizes the need to enhance education for PCPs to adequately utilize the data sharing between the two systems.

PCPs are the only stakeholders that do not have access to view results directly in VISITS. Therefore, VA EHDI provides screening results and follow-up recommendations to PCPs through mailed letters (10,226 letters in 2017). PCPs are requested to notify VA EHDI of any information regarding follow-up appointments, the date, and next appointment facility of their patient. This return exchange from PCPs allows a child to be linked with the appropriate audiology facility to decrease loss to documentation. However, in 2017, only 3,120 (30.5%) return faxes were received from PCPs. VA EHDI will explore the feasibility of providing access to VISITS to PCPs, to increase the information exchange.

Regional Access and Capacity for Audiology Services:
There is difficulty in accessing pediatric audiology facilities in the more rural areas of Virginia. In 2017, 59% of children in the Southwest region who failed or passed with risk during their initial screening are loss to follow-up. This is significantly greater than the state average of 25.7 percent. In the Southwest region, families may require hours of travel to the nearest audiology facility, which causes concern for children obtaining timely diagnosis. Due to extended travel, there is an increased likelihood that the infant has recently slept during the trip, and will not sleep throughout the diagnostic evaluation, resulting in an inconclusive result. Additionally, for children born in 2017, sixty children were still in process, due to incomplete examination with the most recent result being one or both ears were not tested.

In some urban areas of the state, there are not enough audiologists to serve the pediatric population as needed. The Northern and Tidewater regions of Virginia have the highest number of children (6,053) who require outpatient rescreening. There are approximately 10 audiology facilities serving the pediatric populations in Northern and Tidewater regions. VA EHDI will collaborate with the Statewide Learning Community (SLC) to identify methods to address regional concerns.

Diagnosis:
In 2017, 170 children were diagnosed with hearing loss in Virginia. According to the national average, Virginia should be identifying approximately 300 children with hearing loss. VA EHDI has made efforts to identify whether this is a true failure of identification or a failure to report. VA EHDI will explore options to decrease loss to follow-up and loss to documentation of children with hearing loss, through educational resources and collaborative enhancements to the EHDI System.

Recently, VA EHDI has seen a decrease in the age at diagnosis of hearing loss. The average age of a child at diagnosis with permanent hearing loss from January 2018 to August 2018 was 68.4 days. From September 2018 to March 2019, the average age at diagnosis of permanent hearing loss decreased to 47 days. This can be attributed to the implementation of texting into the targeted follow-up. The goal of texting was to ensure that families receive recommendations for follow-up in a timely manner. Additionally, texting helped decrease the time in which families went back for an audiological evaluation. Prior to implementation of texting as a means of communication, the initial contact with families via letter or phone call was conducted between an average of 7-10 days. The texting platform was initiated in August 2018, and families return for an audiological evaluation 7 days faster.

However, VA EHDI recognizes the need to identify more children. In 2017, there were 4,717 follow-up letters mailed out to families who failed their initial hearing screen of which 126 (2.7 percent) returned due to incorrect addresses. VA EHDI recognizes that the population birthing children is more technology driven. VA EHDI will explore options to enhance texting in order to reach more families and improve time of follow-up and meet 1-3-6 guidelines. VA EHDI will explore collaborative efforts with the VDH Communications team to make enhancements to texting in order to add biteable videos that are of importance to families based on their child's hearing results.

Maternal age is a factor in determining whether a child will get timely diagnosis. In 2016, approximately 18 percent of the total births were born to mothers who were between 20-24 years of age, of which 2 percent failed their initial hearing screening. Approximately 62.8 percent of these children who failed their initial hearing screening never received a diagnosis, making this population high risk for loss to follow up. Additionally, of the children who were diagnosed, only 18 percent received a diagnosis within the recommended guidelines of 3 months of age.VA EHDI will explore educational outreach opportunities for this population, in order to reduce loss to follow-up.

Additionally, educational level plays a role in how quickly a child will obtain diagnosis. Mother's with some college credits or college graduates are likely to have their children diagnosed before three months of age (See Table 1 below). VA EHDI will explore options to collaborate with agencies that serve populations with less than high school education. Additionally, VA EHDI will explore options to communicate with families of diverse ethnic backgrounds. Currently, VA EHDI uses interpreting services to convey information in different languages by mail, texts and outgoing phone calls. However, there is a need to enhance communication efforts for incoming calls.

	Diagnostics	
	Hearing Loss	**Hearing Loss by 3 months of age**
Mother's Education Level		
Less than High School	**19**	**10**

High school graduate or General Education Diploma	**44**	**19**
Some College or AA/AS degree	**43**	**20**
College Graduate or above	**60**	**28**
Unknown	**4**	**1**
Total Hearing Loss	**170**	**78**
Maternal Age		
15 – 19 years	**3**	**0**
20 – 24 years	**35**	**18**
25 – 34 years	**92**	**43**
35- 50 years	**40**	**17**
Total Hearing Loss	**170**	**78**

Table 1: Diagnostics by Maternal Education and Maternal Age

VA EHDI explored the feasibility of Tele-audiology in Virginia as a means to decrease loss to follow-up. VA EHDI discussed options with the University of Virginia (UVA) to address the barriers in obtaining timely follow-up in many regions of the state. Southwest regions of Virginia have 59% loss to follow-up, primarily due to transportation issues. It was determined that a satellite location to support Tele-Audiology would not address the loss to follow-up needs in Virginia. VA EHDI will continue to explore options to address these barriers to reduce loss to follow-up.

Border Babies:
Virginia has a large population of children who are born in Virginia but receive services in bordering states. In 2016, approximately 2,000 children were born in Virginia but residents of another state (Maryland, District of Columbia, North Carolina,). When the results of screening are reported to the VA EHDI program, they need to be completed on a paper form, faxed in and thus are often delayed. As a result, those children needing additional testing may not receive timely follow-up. Additionally, a large portion of these children are loss to documentation. VA EHDI recognizes the need to address reporting of children receiving services in bordering states.

Referrals and Outcomes:
Early Intervention (EI):
Since an automated referral system was added to VISITS, the system has proven helpful to ensure that all children diagnosed with hearing loss are referred to EI within 24 hours of entry. In the past, the average time of referral was 7 days, depending on the ability to contact the EI provider.

Additionally, VA EHDI offers referrals to Ear, Nose and Throat (ENT) specialist, Ophthalmology, Genetics, Care Connections for Children (CCC) and family to family support to children who are diagnosed with hearing loss (See Figure 1 below). VA EHDI mails a packet with a letter including information on referral to EI, next steps after diagnosis. This includes information on communication options, community events, and information on agencies who provide services for children who are D/HH. VA EHDI would like to explore options regarding referrals for families by expanding collaboration with stakeholders, program connections, and resources within the EHDI System.

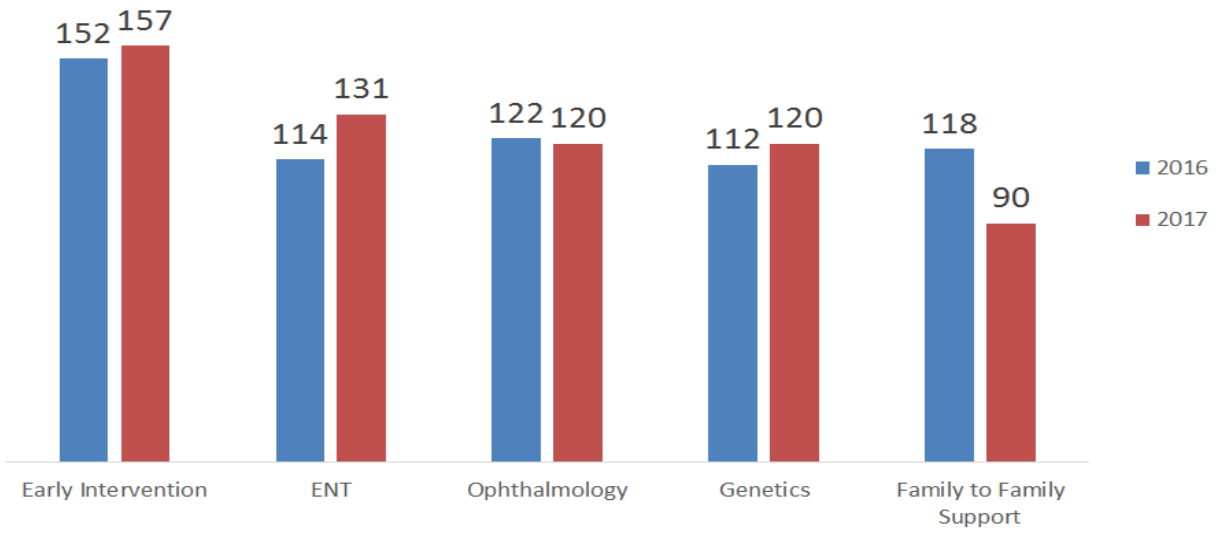

Figure 1: Referrals for Children Diagnosed

In 2017, VA EHDI initiated a secondary call 3-6 months after diagnosis, in order to gather outcomes information and discuss the need for additional resources. During this call, VA EHDI obtains information on enrollment into EI, amplification (if needed), services from specialists: (ENT, Ophthalmology, Genetics), and services from Family to Family (See Figure 2 below).

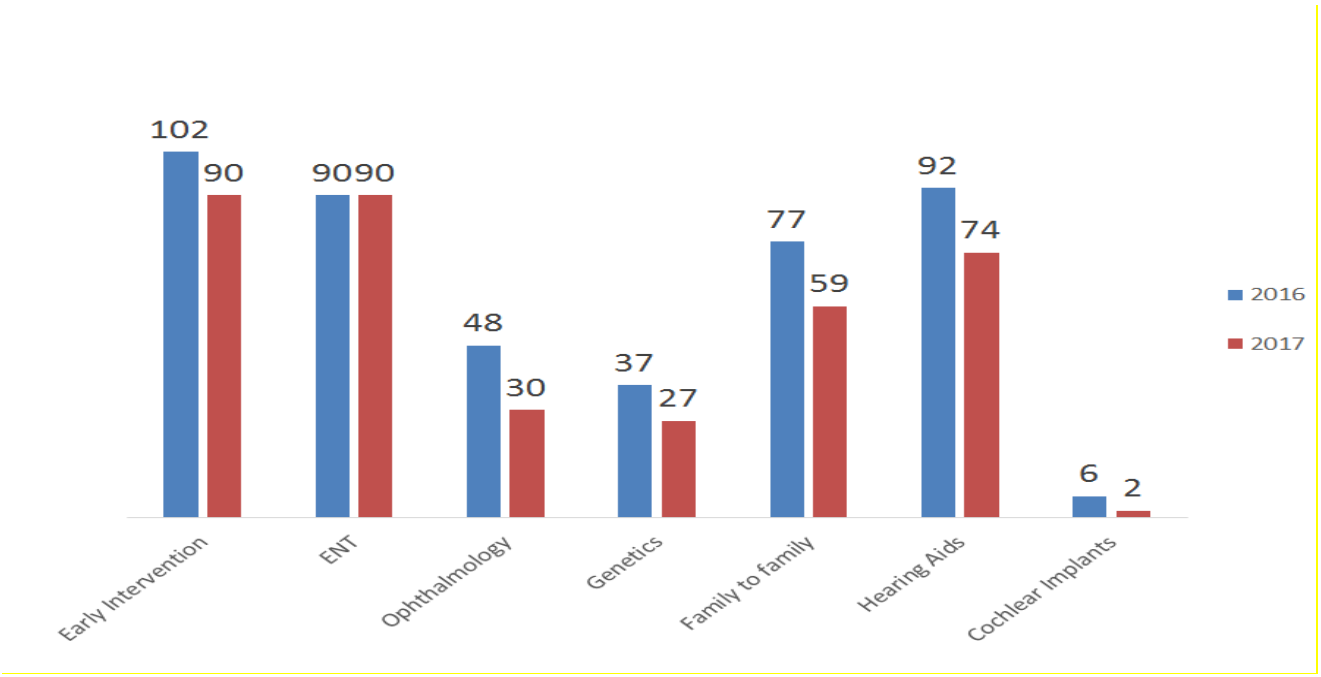

Figure 2: Outcomes for children diagnosed

Enrollment of children diagnosed with hearing loss into EI services continues to be a challenge. VA EHDI has made enhancements to VISITS for EI users to document information including whether the child enrolled or declined services, the reason for declining, and the Individualized Family Service Plan (IFSP) date. In 2017, only 57 percent of children were documented as enrolled in EI services and only 41.7 percent were enrolled by 6 months of age. While the referral rate has increased due to the automated system, the number of children reported to be enrolled in EI services has decreased (see Table 2 below). EI services in Virginia are guided by Family Educational Rights and Privacy Act (FERPA), not HIPPA, and this significantly impacts data capture. VA EHDI plans to expand data capacity via a data sharing agreement with EI to identify gaps in enrollment.

Analysis of VA EHDI enrollment data for 2017 births reflects that children with hearing loss, and one more birth defect, are more likely to be enrolled in EI services. In 2017, 96 percent of children with hearing loss and one more birth defect enrolled in EI services. In 2014, mothers who had less than a high school education or were high school graduate or had a General Education Diploma (GED) were far less likely to enroll in EI compared to mothers who had some college education or was a college graduate. In addition, in 2014, only a little over a third of babies whose mothers were under 20 years were enrolled in EI. In 2017, more than half of the children were enrolled in EI regardless of the mother's age and educational background (see Table 2). VA EHDI attribute this improvement in EI enrollment rate for teenage mothers with less than a high school education to: 1) Targeted follow-up activities, 2) Ensuring that information was at the appropriate health literacy level, and 3) Utilizing Family Educators to provide support and education.

	Intervention	
	Enrolled in Part C EI	**Enrolled in Part C EI by 6 months of age**
Mother's Education Level		
Less than High School	**11**	**8**
High school graduate or General Education Diploma	**23**	**14**
Some College or AA/AS degree	**28**	**24**
College Graduate or above	**33**	**23**
Unknown	**2**	**2**
Total	**97**	**71**
Maternal Age		
15 – 19 years	**2**	**1**
20 – 24 years	**18**	**16**
25 – 34 years	**56**	**38**
35- 50 years	**21**	**16**
Total	**97**	**71**

Table 2. Early Intervention Enrollment by Maternal Age and Education 2017

Cultural backgrounds also play a key role in determining whether families will accept EI services. Analysis showed that African Americans and Asian Americans are less likely to enroll in EI. Families in the more rural regions of the state, southwest and Roanoke, are also less likely to enroll in services. VA EHDI will address the need for increasing enrollment with diverse cultural backgrounds.

Family Support and Parent Engagement:

In previous years, parent collaboration was accomplished through formal agreements. In an effort to increase parental involvement, VA EHDI recognized the need for more informal collaborative efforts; thus, EHDI began promoting community events by parent-led organizations. Additionally,

attendance at these events, allowed a closer understanding of these families' needs, thus opening the door to improved communication. Due to minimal parental involvement in the past, VA EHDI recognized the importance of bridging the gap and increasing communication between parents and the EHDI system and the need to define what parent engagement means in Virginia. The program recognizes that families are the primary stakeholders and the success of children receiving timely services depends upon increasing family engagement. In 2016, in an effort to increase family involvement, VA EHDI allowed parents to become partners by giving them the voice and allowing the program to be driven by parent experiences and stories. In 2017, parent stories were incorporated into each Advisory Committee meeting, which led to an increase in the number of parents as board members and interested parties. VA EHDI will explore options to incorporate stories from deaf adults, fathers, siblings and other family members of children who are D/HH.

In 2012, VA EHDI contracted with The Center for Family Involvement (CFI), at the Virginia Commonwealth University's Partnership for Children with Disabilities. The Family to Family program at CFI provides support for families of children diagnosed with hearing loss. In Virginia, each child diagnosed with a hearing loss has the opportunity to communicate with a Family Educator. Family Educators, parents of a child with hearing loss, serve as a support in the first months after diagnosis. In 2016 and 2017, there were a total of 320 children identified with hearing loss; out of which, 208 children were referred to CFI for family to family support. Of these children, 136 were enrolled in services. Over the last few years, there has been a decrease in the number of families served by CFI. VA EHDI has received feedback from families attending the RLC that there is a need for addressing the change in family dynamics and structure as well as meeting the technological advancements in society. VA EHDI will make an active effort in including fathers in the EHDI systems and determine means to address changes in family dynamics.

METHODOLOGY:

The purpose of this proposal is to enhance VA EHDI's comprehensive, statewide EHDI system of care and to ensure newborns and infants are receiving appropriate and timely services, including screening, evaluation, diagnosis, and enrollment into EI by focusing on:

- Engaging stakeholders in the EHDI System to assure they have information on how to effectively coordinate care for children who are at risk or are D/HH.
- Educating and training health professionals and service providers in the EHDI System to meet 1-3-6 guidelines.
- Strengthening capacity to provide family support and engage families with children who are D/HH in the EHDI System.

VA EHDI continues to focus efforts to strengthen its working relationship with public health and service agencies throughout the state to achieve these goals.

Goal 1: Lead efforts to engage and coordinate all stakeholders in the EHDI System to meet the goals of the program.

Learning Community:

As of May 2019, VA EHDI has successfully established six Regional Learning Communities (RLC). VA EHDI will continue utilizing each learning community to

increase stakeholders' knowledge and engagement within the VA EHDI system. This will consist of efforts to increase: 1. Number of trainings provided to the learning communities; 2. Participation in parent/professional training; and 3. Number of participants that attend the RLC meetings.

VA EHDI, with assistance from the Learning Community Coordinator, established each RLC. It is the goal that once each RLC is fully established, they will be independently managed by local leaders, including one parent and one professional. VA EHDI intends to establish local leadership in all regions by the end of 2019 and will maintain an active role in each RLC and provide support to the Learning Community leaders, as needed. In 2020, VA EHDI plans to establish a Statewide Learning Community (SLC), which will include two to three representatives from each RLC including at least one of each: PCPs, Audiologists, hospital representatives, Parents, and Early Intervention Providers. Other stakeholders could include ENTs, Speech and Language Pathologists, Family to Family support organizations, and Deaf adults. The SLC will meet annually to address statewide concerns and to improve services for D/HH children statewide.

The Northern Virginia RLC began work on Virginia's Shared Plan of Care (SPoC) for parents, Audiologists, PCPs, and Early Intervention providers in 2018. The SPOC for parents includes current and accurate information and decisions about full range of assistive technologies and communication modalities. In efforts to ensure the effectiveness of the SPoC, VA EHDI conducted QI activities with parents and professionals. Based on these activities an updated version of the SPOC was established in 2019. There is a need for additional training for professionals prior to using the SPOC; therefore, a live/virtual training will be conducted for all professionals. In collaboration with the Communications team at VDH, VA EHDI will post the virtual trainings to the EHDI website and monitor the number of views. Additionally, the team will promote the SPoC documents and trainings via the RLC and SLC. A quality assessment survey will be conducted, and the feedback will be utilized to make enhancements as needed.

Improving Hearing Screening:

Increasing Hearing Screening rates:

VA EHDI is aware of the need for improved screening rates in populations that choose to birth their children outside of the hospital setting. To address this gap, in 2017 VA EHDI began outreach to midwife birthing facilities to provide education on the importance of timely hearing screening. VA EHDI is working to increase the number of midwife birthing facilities to gain access to VISITS in order to report children who are not screened at birth. This will allow VA EHDI to provide timely follow-up and encourage screening before 1 month of age. In the past, VA EHDI would not be aware that these children had missed initial screening or would get the information much later at which point parents may refuse screening due to the child's age.

At a RLC meeting, a parent spoke about the home birth of her child. She mentioned that there were no obvious language concerns until around 12 months of age when the child was not developing language properly. At this point, a hearing test was performed and the child was diagnosed with hearing loss. She noted that the child was seen by a pediatrician right after birth and at regular intervals thereafter; however, there was no mention that hearing screening was a necessary test after birth. Additionally, midwives who attend RLC meetings have stated that they do recognize the importance of hearing screening and need for more education for families who use their

services. They shared that families would be more likely to have their child's hearing tested, if they could be performed right after birth instead of asking their families to go see another medical specialist shortly after birth.

Recently, the VA EHDI Program exhibited at the *Enhancing Safety through Collaboration in Maternity Care*, where many midwives and out of hospital birthing facilities were in attendance. VA EHDI will continue to attend similar events to enhance their working relationship with midwives to ensure all children receive timely hearing screening. To address this gap, the team will consider the feasibility of purchasing screening equipment (13), of which 12 will be distributed to midwives and/or home birthing centers throughout the Commonwealth to encourage screening after birth. These facilities will receive training on best practices for conducting newborn hearing screens.

Additionally, VA EHDI will keep one screening equipment to utilize in house or at external events to promote initial hearing screens at local community events like health fairs with Virginia Head Start. The team will obtain training to conduct the hearing screenings and explore the feasibility of travel to areas with higher rates of loss to follow-up, and host screening days for children who need initial screening or rescreens. In addition, VA EHDI will conduct site visits and training for birthing hospitals and birthing facilities to ensure they have adequate information to conduct timely hearing screening. VA EHDI has maintained a high rate of completion of screening for children born at birthing hospitals and strives to ensure that all children complete the screening process by one month of age, regardless of where they are born.

Border Babies:
Virginia recognizes the need for improved communication and reporting of results among bordering states. Recently, site visits to audiology facilities and birthing hospitals in bordering states were conducted to discuss options on how to appropriately address the loss to follow-up and loss to documentation of border babies. Virginia plans to provide access to VISITS for audiology facilities and birthing hospitals in bordering states. There will be a pilot in Year 1 with an audiology facility and multiple hospitals in Washington D.C. These organizations will be provided appropriate training and education on entering results electronically into VISITS. Additionally, VA EHDI plans to expand the referral network to include out of state facilities, as these may be more convenient for families living close to the border.

At risk children:
The VISITS database captures risk indicators for delayed onset of hearing loss on all children at birth, based on recommendations from the Joint Commission on Infant Hearing (JCIH). VA EHDI recognizes the need for further training on identifying children who are at risk for developing delayed onset of hearing loss. VA EHDI is working in collaboration with hospital screeners and audiologists to develop a virtual training for at risk children. This training will provide guidance on how to identify risks and provide information on next steps to assist hearing screeners with appropriate information to provide to families based on associated risks.

Recently, an enhancement was made to the at risk follow-up letters to include the specified risk indicators captured at screening. Currently, VA EHDI sends follow-up letters and texts for at risk children shortly after birth to recommend diagnostic testing between 12-24 months of age. In order to provide more timely recommendations, a plan has been developed to send a delayed letter and

text to children around 12 months of age. Additionally, in September 2020, Virginia will begin screening for congenital Cytomegalovirus (cCMV) for those who fail their initial hearing screen. VA EHDI will work with stakeholders to develop education on the next steps and provide education on cCMV as a risk indicator for hearing loss.

Efforts to reduce LTF:
Although, there have been slight improvements in the loss to follow-up rate from 26.0 percent in 2016 to 25.7 percent in 2017, there is a need for improvements in follow up processes, training of providers and system enhancements to support timely reporting. VA EHDI and the Epidemiologist will monitor and analyze loss to follow up and loss to documentation. Regional analyses will be conducted to improve follow up procedures based on the regional needs and barriers.

VISITS is linked to the EBC registry, any child that is created in EBC automatically transfers into VISITS with data transfer of demographic and primary contact information. This creates a list for each birthing facility to easily enter hearing screening results. There was feedback received from audiologists and rescreeners regarding difficulty with searching for children in VISITS. Audiology and rescreening user roles have stringent search criteria in order to meet Health Insurance Portability and Accountability Act (HIPAA) requirements.

In order to improve reporting and decrease loss to documentation rates, system enhancements were made to create a list of children that were referred to or previously seen at the facility in order for audiologists to easily access the child's records. Additionally, enhancements were made to include a search by phone number feature into VISITS to allow audiologists to easily access child records. VA EHDI follow-up team will monitor these lists to see how many children are pending entry of hearing screening and/or diagnostic results to ensure compliance. The timely entry of initial hearing screening results is key to meeting 1-3-6 guidelines. Facilities out of compliance will receive communication from VA EHDI to provide assistance if results are not reported within 7-14 days after screening or diagnosis. Additionally, system enhancements will be considered to identify primary care providers in an effort to reduce lost to documentation.

There is a need for continued site visits to birthing facilities, audiology, hearing rescreening offices, and EI facilities in order to provide updated guidelines, review systematic enhancements and provide training to any new staff. In order to address this need with limited staff, VA EHDI will create and conduct a live virtual annual compliance training, which will be recorded. The training will consist of reviewing compliance guidelines, overview of system usability, training on systematic enhancements, importance of education on identification of patient and family centered medical home, and other communication within the EHDI System. VA EHDI will post this training on the EHDI website for those who are unable to attend or those who obtain new staff. Additionally, all new VISITS users will be required to complete this training prior to gaining access to the database.

VA EHDI conducted a pilot with HV programs in the Northern Virginia region to provide education for prenatal mothers and found that many families were not aware that their child would be getting a hearing screening. Prenatal and postnatal education is important to increase awareness of hearing screening prior to birth and allows the families to be prepared with next steps if their child fails the initial hearing screening. Therefore, a meeting with the WIC program determined

that Prenatal and Postnatal fact cards were the most effective method to provide education to the populations served by their program. VA EHDI was aware of the need to create culturally sensitive and appropriate literacy level materials to ensure a broad reach to the populations being served. The Prenatal and Postnatal fact cards are English on one side and Spanish on the other and are at seventh grade reading level, like many other VA EHDI materials. The Prenatal and Postnatal fact cards were developed in 2018, and distributed to approximately 3,000 Home Visiting programs and WIC agencies throughout the Commonwealth. Since incorporating these materials in 2018, VA EHDI has received positive feedback from many parents and stakeholders regarding these educational materials at conferences, meetings and events. The promotion of these materials will continue in collaboration with Home Visiting programs and WIC agencies. VA EHDI will explore the feasibility of using these materials with Obstetricians and birthing facilities to increase prenatal awareness of hearing screens.

VA EHDI has noticed that gender roles and family dynamics are changing. In the past, VISITS database only captured the mother to be the primary contact; currently, enhancements have been made to caregiver roles as Parent I and Parent II. In order to address these changes, VA EHDI will incorporate diversity in the EHDI systems to address differences in: race, gender, socioeconomic status, ethnicity, sexual orientation, age, physical disabilities, religious beliefs and political beliefs.

VA EHDI will monitor and analyze the current follow-up plan to determine methods for improvements to decrease loss to follow-up and loss to documentation. VA EHDI provides follow-up for children from birth to 36 months. Follow-up letters are sent to families and PCPs, and text messages are sent to families upon entry of screening and diagnostic results. Additionally, VA EHDI follow-up team will communicate with families via phone to provide next steps for children in need of immediate screening and/or diagnosis (See Figure 3 below)

Due to expanding follow-up to 36 months and limited staff to provide adequate follow-up, options will be explored to enhance the follow-up plan to incorporate more automated follow up such as robot calls, and voice text messages. Additionally, VA EHDI will train all team members in follow-up activities. With the cCMV screening tentatively set to begin in September 2020, VA EHDI will incorporate follow-up for children who are screened for cCMV into the existing VA EHDI Follow-up plan.

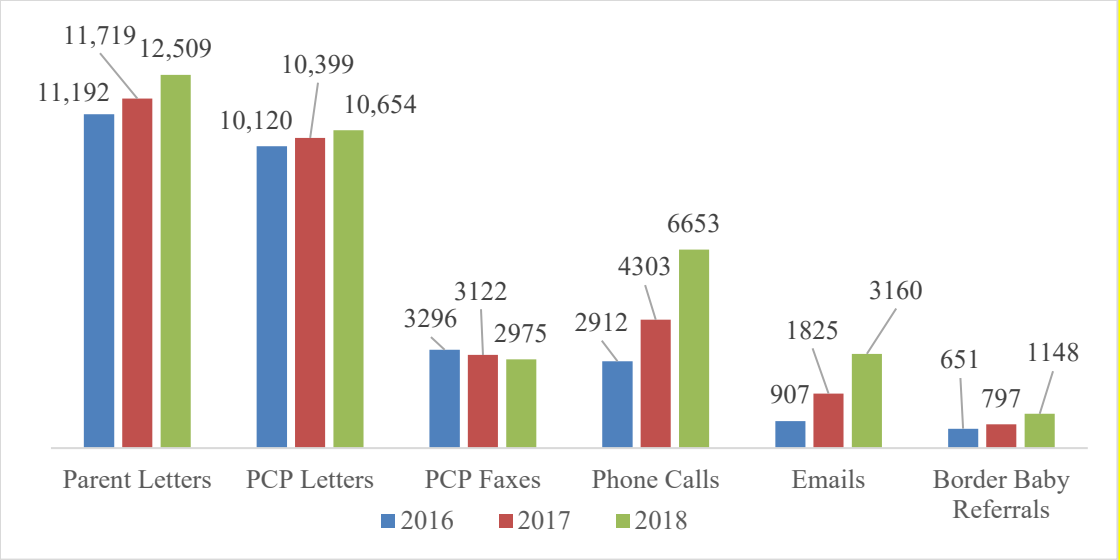

Figure 3: Overview of VA EHDI Follow-Up 2016-2018

Advisory Committee:
VA EHDI currently has an established multidisciplinary Advisory Committee (AC), which meets quarterly to provide advice on potential mechanisms to achieve project strategies, to discuss upcoming partner events, possible future partnerships, and EHDI program updates. The committee is currently comprised of members of the following organizations:

- Birthing hospitals
- State agencies responsible for the implementation of Part C
- State Chapter of the American Academy of Pediatrics
- State Title V Programs
- Leadership Education in Neurodevelopmental and Related Disabilities Program
- State school for the Deaf
- State offices of the Deaf and Hard of Hearing
- Family Organizations (Family-to-Family, Hands & Voices)
- State Medicaid Agency
- Parents of deaf/hard of hearing children

Currently, the committee is comprised of approximately 30 percent parents/family members of children who are D/HH and individuals that are D/HH. The AC will be co-led by a parent or family member of a child who is D/HH and a professional. VA EHDI team will work to include representatives from organizations like WIC, Early Head Start, and other family organizations on the AC. The AC and VA EHDI team will work to recruit more families to increasing family engagement within the EHDI system. Additionally, they will work to promote education of stakeholders to encourage timely screening and reduce loss to follow up. VA EHDI will encourage stakeholders and parents at AC to attend the EHDI annual meeting to ensure that the AC is up to date on current guidelines and recommendations. The RLC and SLC updates will be provided at

each meeting to ensure that the AC members are able to provide appropriate guidance for programmatic support and improvements in meeting 1-3-6 guidelines.

Quality Improvement:
Previously, VA EHDI had a QI Coordinator who would lead efforts to conduct QI activities consistently. Since QI is essential to VA EHDI, QI activities will now be carried out as a team effort by the EHDI team and stakeholders involved in the EHDI Systems. VA EHDI has established the parent perspectives workgroup, a subcommittee of the Advisory Committee, to review EHDI Processes, materials, publications and texting. The workgroup consists of parents of children who are D/HH, other EHDI Stakeholders, and the VA EHDI team. They have provided feedback on the prenatal and postnatal educational cards, assisted with updating the follow-up letters sent to families and PCPs, and developed messaging for follow up text messages. This workgroup will continue to provide assistance with QI activities during this project period.

VA EHDI will work closely with the 12 birthing facilities who receive screening equipment to monitor the screening rate and loss to follow up for children who are born at out of hospital birthing facilities. Additionally, VA EHDI will work with the Epidemiologist to develop a baseline for at risk children. This will provide accurate information on which birthing facilities are not reporting risks as well as identify commonly occurring risk indicators in children who are later identified with hearing loss. Based on QI findings, VA EHDI will determine appropriate strategies to enhance the education of stakeholders and provide targeted follow up.

Goal 2: Educate and train health professionals and service providers in the EHDI system.
Technological Enhancements:
VA EHDI recognizes that a large portion of the population birthing babies is between 25-35 years of age, thus it is imperative to incorporate technological advancements into the EHDI Systems. Recently, VA EHDI collaborated with CDC to distribute the EHDIPALS App to parents at two birthing hospitals in Virginia (Southside Regional Medical Center and Johnston Memorial Hospital) for children who failed the initial screening. The App helped parents virtually keep track of upcoming appointments with reminder notifications and received positive feedback from many parents and providers. However, providers expressed interest in needing additional messaging for families to understand the results of the test and determine next steps in follow up. Biteable videos will be created to provide clear messaging based on the results of the hearing screening or diagnosis. These videos will be available on the updated *Your Baby's Hearing Results* brochure via QR code. Additionally, the videos will be used in the enhanced follow up texts to families.

Shared Plan of Care:
The SPOC was developed to provide overall care coordination and will be utilized as a means for providers to communicate with each other regarding next steps in the referral process for a child diagnosed with hearing loss. With funding from CDC, VA EHDI is working to incorporate the electronic SPOC (eSPOC) into the VISITS database. The following providers should have access to the eSPOC: PCPs/Medical home, Audiologists, EI Providers and Family to Family. Because Audiologists and EI Providers utilize VISITS already, it will be seamless to provide them access to the eSPOC. There will be a new user role generated for the Family to Family Program and access will be granted to users from the Center for Family Involvement (CFI) at Virginia Commonwealth University (VCU) as needed. In 2014, a linkage between VIIS and VISITS was created, which

provides the child's medical home with access to hearing screening results. VA EHDI will explore options to expand this linkage to allow the medical home to view the eSPOC or consider the feasibility of providing them access to VISITS. Education and training will be provided to all stakeholders and a survey will be conducted on usability.

Training and Educating Stakeholders:
While automating the VISITS system for stakeholders is a positive outcome, this also decreases the direct interaction with stakeholders. Quarterly communication will be provided to all stakeholders to ensure that there is open communication regarding current EHDI updates, enhancements to VISITS and information about upcoming events. Additionally, materials will be branded to allow increased awareness of the program. VA EHDI will also develop and maintain an educational library on the EHDI website with trainings, parent stories, and up to date research. VA EHDI plans to continue and enhance training to providers statewide to stress the importance of: 1) Meeting the 1-3-6 guidelines in a child's development and language acquisition; 2) Timely reporting to VA EHDI and communication of results to families; 3) Identification and explanation of risk indicators, to provide the family with clear recommendations for next steps in follow-up. 4) Identification of and benefits of patient and family- centered medical home.

In 2018, VA EHDI held the first training seminar, Continuity of Care, which was geared towards training EHDI stakeholders. Due to inadequate space, this seminar was limited in the number that could attend. In 2019, VA EHDI hosted a larger training seminar, Trauma Informed Care. This second seminar was very well received with many in attendance stating, "It was the best thing I have attended in 10 years." Based on the positive feedback, VA EHDI will continue hosting these training seminars to engage parents and professionals.

VA EHDI also provides virtual trainings regarding the VISITS database, which will be a requirement for all new users to complete. Education will be provided on all new enhancements in VISITS to ensure that stakeholders are aware of any changes prior to them being implemented. In order to bridge the gap with EI Providers and data sharing, VA EHDI will look into the feasibility of uploading data into a longitudinal data sharing system.

Since incorporating texting as a means of communication with parents, there has been positive feedback from all stakeholders, and a decrease in time to follow up. VA EHDI will explore texting professionals regarding upcoming events, meetings, and general informational texts regarding 1-3-6 guidelines. Recently an AC meeting was cancelled the evening prior, due to inclement weather the day of the meeting. The AC has participants that live in all regions of the state and some travel a large distance to attend the meeting. Due to the last minute cancellation, VA EHDI had to individually call the Committee members to inform them of cancellations. VA EHDI could use the texting platform as a means of effective communication in the event of an emergency.

Currently the *Your Baby's Hearing Results* brochure is used for all children who receive newborn hearing screening after birth regardless of the results. Providers often work in auto mode and thus parents may not receive targeted next steps when children do not pass. Therefore, VA EHDI plans on updating the brochures to fact cards which are specific for the hearing results: failed, missed, passed, fail with risk, and passed with risk. Each fact card will be color coded based on the result and provide targeted information on follow up. This targeted approach will allow providers to offer

more result specific information to those families needing follow up. When updating these materials, the diversity in family dynamics will be addressed. VA EHDI will provide training and education to all birthing facilities prior to distribution of the enhanced brochures.

In 2018, VA EHDI collaborated with UVA to create a training module for PCPs to provide education on the EHDI goals and next steps for children in need of follow up. The training module will be enhanced to incorporate new screening methods for cCMV, the SPOC for children with hearing loss, and updated information on children at risk. A survey will be conducted of stakeholders regarding this module.

An effective way to educate a large group of stakeholders and increase awareness of the EHDI goals is by exhibiting and/or presenting at conferences or events. VA EHDI has exhibited at various conferences over the last few years including:

- Creating Connections to Shining Stars (Early Intervention Providers),
- Virginia Society of Otolaryngology (VSO) Annual Meeting (ENTs),
- Opening Doors Unlocking Potential,
- James Madison Ruth Symposium (Audiologists),
- Hands and Voices Leadership Conference
- Deaf and Hard of Hearing day at Kings Dominion (Families of deaf or hard of hearing children).

While at the VSO annual meeting, there was an interest from ENTs in having set guidelines for children in the EHDI systems. The EHDI protocols for hospitals, Audiologists, and PCPs, were recently updated in 2018. VA EHDI will work on establishing EHDI Protocols for ENT Providers by developing an ENT workgroup, a subcommittee of the AC. Continuous education will be provided to stakeholders at conferences and events during this project period. Additionally, VA EHDI will work with stakeholders in AC to present to a large group of stakeholders at meetings, conferences or virtually via webinar.

Collaborating with EHDI Partners:

The AC consists of various stakeholders who are involved in improving services for children who are at risk for hearing loss or children who are D/HH. VA EHDI has formed several subcommittees in order to improve participation from stakeholders and provide education. Additionally, during each AC meeting EHDI partners are invited to speak regarding their program or field of expertise. These include a Geneticist, a home visitor, a member of VIIS Staff, VA LEND representative, and a member of the Care Connections for Children (CCC) Program with the Children and Youth with Special Health Care Needs (CYSHCN). Efforts will be made to continue to increase collaboration with other agencies to provide education to stakeholders at the AC meetings. The National Training and Resource Center has provided technical assistance and training for EHDI stakeholders in Virginia and HRSA's EHDI project officer has provided guidance on achieving project goals. VA EHDI will continue to collaborate with state, local and federal EHDI partners to improve services for D/HH children. Additionally, VA EHDI also promotes community activities via social media sites, and via phone calls and mailings to families of children who are diagnosed with hearing loss.

Goal 3: Family Support and Engagement for Children Who are D/HH:
VA EHDI ensures collaboration and partnerships with family based organizations and programs to support children who are D/HH. Efforts will be made to promote family leadership and active family engagement within EHDI Systems. In 2012, a relationship was established with the Centers of Family Involvement (CFI) at VCU to provide family support for children diagnosed with hearing loss. There has been a recent trend in decreased referrals to the CFI at VCU and there is a need for enhancing the scope of services to address the changes in family dynamics and societal advancements. Currently, the Family Educators at CFI contact families via phone once a referral is accepted; however, the Family Educators have expressed that they are unable to reach some families by phone. Feedback from families suggested that virtual support options be available, as they can be accessed in a non-traditional manner, 24 hours a day. With increased societal advancements and fast-paced lifestyles, families need support to accommodate their schedules and needs.

In order to increase family engagement in EHDI systems, VA EHDI began attending local community events by family-led organizations such as Hands and Voices, Families to Families and Parent Child Advocate program. This has helped bridge the gap between parents and professionals, thus building the collaborative relationship that exists today. There are plans to enhance this collaboration by extending financial support to the family led organizations to provide community events for families and their children who are D/HH. Some events held in past years include ice cream socials in the park, skate night, and attending a Flying Squirrels baseball game. VA EHDI will determine the feasibility of additional social activities in collaboration with the Center for Family involvement. CFI will provide fiscal support to existing local parent organizations in order to host these community events. Additionally, Virginia will continue to collaborate with HRSA's Family Leadership in Language and Learning Center (FL3) to ensure that families with children who are D/HH have access to essential resources needed for successful development.

In 2019, VA EHDI attended parent support activities throughout the state to collaborate with families and programs for children with a hearing loss. The annual CARE Project was hosted in Virginia, and stakeholders and parents supported in providing care for children when their families attended seminars and workshops. The Family Educators will continue to gather information and additional resources within their region for children who are deaf or hard of hearing. This information sharing between the Family Educators and VA EHDI will enhance efficiency within the EHDI System. Family Educators will continue to provide 1:1 support to families of newly identified children who are D/HH.

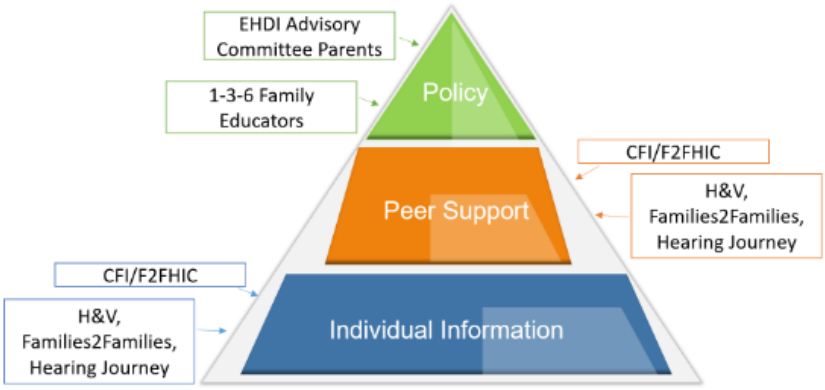

Figure 4: Virginia's Family Engagement Model

In 2019, Virginia Joint Commission of Health Care (JCHC) implemented a study on Senate Bill (SB) 1741 to explore available resources and services for D/HH children. SB 1741 explored policy considerations to determine which agency would be the leading resource center, explored language acquisition and literacy outcomes, and availability of deaf adult mentorship for children who are D/HH. VA EHDI recognizes the need for children who are D/HH to access the support of a deaf adult. VA EHDI will determine the feasibility of providing access by exploring existing programs for deaf adult mentorship and will await decision from SB 1741 for guidance. In the meantime, VA EHDI will continue to collaborate and discuss with other programs the feasibility of a Deaf Mentor program in Virginia. Additionally in September 2020, Virginia will begin targeted screening for congenital Cytomegalovirus (cCMV) for those children who fail initial hearing screening. Virginia anticipates that incorporating this mandate will significantly affect all aspects of the program including reporting, follow-up, and diagnosis rates.

Ongoing Activities:
VA EHDI will continue its ongoing efforts to ensure newborns and infants are receiving appropriate follow up by:

- Continuing to track and provide follow-up to infants born in Virginia;
- Providing resources and referrals to parents of children identified with hearing loss including decisions about the full range of assistive technologies and communication modalities;
- Maintaining collaborative partnerships with stakeholders;
- Reviewing and revising the VISITS reporting system logic;
- Enhancing VISITS to increase use and automate existing manual processes;
- Providing VISITS trainings for all system users; and
- Conducting site visits to hospitals, audiologists, PCPs, and EI providers to provide technical assistance and identify opportunities for improvement

Dissemination Plan:
TESA will share successful strategies that other states and territories may replicate for use in their EHDI programs by the following methods:

- Successful methodology and results will be shared throughout the duration of the project at the National Center for Hearing Assessment and Management (NCHAM) regional meetings.
- Resource materials will be made available on the website for public viewing and replication
- Abstracts will be submitted about successful strategies implemented through TESA.

WORK PLAN: (See attachment 1 for detailed work plan):

Goal 1: Lead efforts to engage and coordinate all stakeholders in the EHDI System to meet the goals of the program

- **Objective 1.1:** Utilize learning communities to increase stakeholder's knowledge and engagement within the EHDI system.
- **Objective 1.2:** Expanding infrastructure to support hearing screening for children up to age 3. Maintaining and/or improving partnerships for information sharing, referral and training.
- **Objective 1.3:** Support infrastructure that ensures 1-3-6 guidelines and reduces loss to follow-up and loss to documentation
- **Objective 1.4:** Conduct EHDI AC meetings to engage stakeholders in EHDI
- **Objective 1.5:** Incorporate stakeholders in developing quality improvement strategies to meet EHDI system goals.

Goal 2: Educate and train health professionals and service providers in the EHDI System

- **Objective 2.1:** Utilize technological advancements to meet the 1-3-6 recommendations
- **Objective 2.2:** Promote importance of continual screening, diagnosis and intervention up to age 36 months
- **Objective 2.3:** Conduct outreach and education to health professionals and service providers
- **Objective 2.4:** Collaborate with local, state and federal EHDI partners to meet EHDI system goals.

Goal 3: Strengthen capacity to provide family support and engage families with children who are DHH.

- **Objective 3.1:** Develop and maintain active family engagement and leadership efforts for families of children identified through newborn screening. Provide programmatic and fiscal support of family leadership and engagement.

RESOLUTION OF CHALLENGES:

VA EHDI serves its infants in conjunction with the CDC 1-3-6 guidelines. The primary goals of TESA are to ensure all Virginia infants receive initial screening, follow-up if needed, diagnosis, referral and enrollment in appropriate intervention services that will optimize their language, literacy, and social-emotional development. In progression of the completion of the grant's goals, the possible challenges and proposed resolutions are listed below:

Staff Recruitment and Training:

The recruitment process of a new Project Coordinator is essential to facilitating efficiency in the EHDI system. This position is currently vacant, VA EHDI has begun the recruitment process. The Project Coordinator will execute grant related activities to ensure methodical implementation of

grant meetings, related events, and budget management. In previous years, the Project Coordinator position was funded as a wage position; however, turnover rate for wage positions are unsustainable due to lack of work hours and benefits. Since 2016, there have been seven people in the VA EHDI wage positions. Thus, the Project Coordinator position will be funded as an FTE in this project period to ensure consistency in staffing to support grant functions.

Sustainability:
Currently two VA EHDI team members are funded by Title V and would be able to continue grant related activities as needed. VA EHDI will continue to use in-kind support from interns to support programmatic projects. Additionally, automation of Follow-up activities will decrease the staff resources needed while continuing to meet 1-3-6 guidelines.

Engagement of families:
VA EHDI will continue to collaborate with family members of children who are D/HH. Integration of enhancements to the EHDI system will increase collaboration efforts amongst families involved in the follow-up process. Virginia strives to involve families from each region of the state by incorporating them in events, conferences, and meetings. However, family involvement from certain regions may be challenging to pursue. VA EHDI and CFI will make efforts to use efficient communication technologies to increase family participation.

Data:
VA EHDI is aware that more children are receiving a range of services including but not limited to: genetics counseling, ophthalmology, hearing aids, and EI services, compared to the data received from VISITS. In order to capture additional data, VA EHDI will continue to make enhancements to follow-up.

Limited Resources:
VA EHDI will purchase screening equipment to aid in hearing services to infants born out of the hospital. Screening equipment will be given to out of hospital facilities, as well as the VDH staff in order to host screening events across the state to address gaps in follow-up.

EVALUATION:

Comprehensive Project Evaluation:
The evaluation plan will be reviewed annually by the Advisory Committee to include the process and outcome measures. The plan will evaluate the effectiveness of strategies implemented to address barriers and challenges and the extent to which the program-specific objectives have been met. The primary data source for evaluation will be the VISITS database. All components of the EHDI 1-3-6 process will be evaluated, with special emphasis on: outcome measures for infants diagnosed with hearing loss and providing training and education to health professionals and service providers on EHDI systems. To evaluate the knowledge of health professionals about EHDI, VA EHDI team will prepare and conduct qualitative measures such as surveys. Minutes and notes from meetings will document stakeholder involvement and family engagement. Additionally,

virtual trainings and educational materials will be monitored to evaluate knowledge of health professionals on EHDI systems.

Evaluation Measures:

The following evaluation measures will assess to what extent the program objectives are met.

Goal 1: Lead efforts to engage and coordinate all stakeholders in the EHDI System to meet the goals of the program

1. Increase from 98 percent to 99 percent the number of newborns and infants who receive timely screening by 1 month of age.
    - Numerator: Children who receive screening by 1 month of age.
    - Denominator: Total Births in Virginia
    - Measure Frequency: Annually
    - Measure Source: VISITS
2. Increase from 64 percent to 85 percent number of infants that completed a diagnostic audiological evaluation no later than 3 months of age.
    - Numerator: Children who receive a diagnostic evaluation by 3 months of age
    - Denominator: Children who fail their most recent hearing screening
    - Measure Frequency: Annually
    - Measure Source: VISITS
3. Increase from 76 percent to 80 percent number of infants who are identified to be DHH that are enrolled in EI services by 6 months of age.
    - Numerator: Children who are enrolled in EI services by 6 months of age.
    - Denominator: Children whose most recent diagnostic evaluation reports a permanent hearing loss.
    - Measure Frequency: Annually
    - Measure Source: VISITS
4. Increased by 10 percent the number of health professionals and service providers trained on key aspects of the EHDI system.
    - Numerator: Number of on-site trainings, number of individuals who completed online trainings
    - Denominator: N/A
    - Measure Frequency: Annually
    - Measure Source: EHDI program records, EHDI training website records

Goal 2: Educate and train health professionals and service providers in the EHDI System

- Increase family involvement in Advisory Committee to a minimum of 25 percent parents or family members of infants or children who are deaf or hard of hearing. Numerator: Number of members in Advisory Committee who are parents or family members of infants or children who are deaf or hard of hearing and/or deaf or hard of hearing individuals
- Denominator: Number of all members in Advisory Committee
- Measure Frequency: Quarterly
- Measure Source: Advisory Committee Membership List

1. Increase by 10 percent the education and training for healthcare professionals and service providers.
    - Numerator: Number of healthcare professionals and service providers who received training.
    - Denominator: N/A
    - Measure Frequency: Annually
    - Measure Source: EHDI program records, EHDI training website records

Goal 3: Strengthen capacity to provide family support and engage families with children who are DHH.

1. Number of parent support activities or events attended by VA EHDI staff
    - Numerator: Number of parent support activities or events attended
    - Denominator: N/A
    - Measure Frequency: Annually
    - Measure Source: EHDI program records
2. Number of families served by 1-3-6 Family Educators
    - Numerator: Number of families served
    - Denominator: N/A
    - Measure Frequency: Quarterly
    - Measure Source: CFI Report

TECHNICAL SUPPORT CAPACITY:

Project Personnel

The following positions are members of the VA EHDI team and will be responsible for performing assigned tasks or activities that are described in the Work Plan. Staffing supports the 1-3-6 model aiming to assure timely follow-up at each stage of the EDHI process. See Attachment for Job Descriptions and Attachments for Biographical Sketches of Key Personnel.

- The **Public Health Nurse Manager (NM)** oversees the Virginia Department of Health's Newborn Screening and Birth Defect Surveillance Programs. This position provides formal supervision to staff in the Early Hearing Detection & Intervention (EHDI), dried blood spot, and Critical Congenital Heart Disease (CCHD) screening programs, as well as to the birth defects surveillance program. Major responsibilities focus on budget development, monitoring, legislative and policy development, procurement, administration of grants, quality assurance of service delivery, and subject matter expertise to multiple internal and external stakeholders.
- The **EHDI Coordinator (EC)** (Full time) manages Virginia Newborn Hearing Screening Program, provides direct supervision to EHDI team, coordinates VA EHDI Advisory Committee meetings, conducts site visits and trainings, monitors and provides surveillance of hospitals, evaluates activities, collaborates with Family to Family & the VA Hearing Aid Loan Bank, manages contracts & budgets, reviews and improves efficiencies, implementation of regulations and protocols for PCP, audiologist and hospitals. The EC works with EHDI team to improve outcomes and monitors follow-up processes.
- The **Follow-up Coordinator (FC)** (Full time) contacts parents in the 1-3-6 process, provides support to the Follow-up Specialist, PC, and educates PCPs on hearing loss. The FC contacts parents and providers to assure infants with a diagnosed hearing loss are linked

to early intervention services and other resources prior to 6 months of age. The FC also contacts these families 3 to 6 months after initial contact to gather outcome data and provide additional resources as needed. The FC will be responsible for training and technical assistance to Hospitals, Audiologists, Early Intervention Providers, and PCPs as well as oversee the enrollment of audiologists on the EHDIPALS site.This position will collaborate with Home Visiting agencies, Women and Children (WIC), and Early Intervention. The FC monitors and analyzes trends throughout the complete follow up process. The FC will be responsible for overseeing technical aspects of the Child Health Information Data system (VISITS), including system enhancements and surveillance reports.

- The **Follow-up Specialist (FS)** (Full time) contacts parents and providers to assure screening and rescreening after failed initial prior to 1 months of age. Additionally, FS will provide follow up for pass with risk children and children who are screened for cCMV. The FS monitors and provides follow-up to children with transient and unknown hearing loss to ensure that children in process are provided a final diagnosis. The FS will also work closely with audiologist to ensure early diagnosis.
- The **Project Coordinator (PC)** (Full time) collaborates with statewide learning communities and other community resources to ensure families receive services. The PC will manage HRSA grant activities and facilitate reporting to MCHB. The PC will collaborate with follow-up staff, Advisory Committee and stakeholders to facilitate quality improvement activities. The PC will monitor and provide surveillance of EHDI - IS to identify need for quality improvement.
- The **cCMV Coordinator (CC)** (Full time) CC will manage the cCMV screening program, coordinates site visits, monitors cCMV screenings and provides surveillance reports to hospitals. This position will provide follow-up and education to providers and parents.
- The **Program Administrator (PA)** (Full time) will provide assistance to the VA EHDI program in planning and preparation of the EHDI Advisory Committee meetings, conferences, and other events. The PA manages purchasing, travel requests, and securing communication services. The PA monitors incoming and outgoing correspondence between the VA EHDI program and stakeholders.
- The **Maternal and Child Health Epidemiologist (EPI)** performs statistical analysis of data to drive programmatic decisions, and performs quality assurance activities. EPI completes all metric reporting requirements for multiple grants and federal/state entities. EPI also reports and presents data to inform and educate families and stakeholders.

New Materials Published:

1. The Early Hearing Detection and Intervention Audiology Protocols: The VA EHDI Program in collaboration with the Advisory Committee revised, printed, and distributed in 2018
2. The Early Hearing Detection and Intervention Hospital Protocols: The VA EHDI Program in collaboration with the Advisory Committee revised, printed, and distributed in 2018
3. The Early Hearing Detection and Intervention Primary Care Provider Protocols: The VA EHDI Program in collaboration with the Advisory Committee revised, printed, and distributed in 2018
4. The Virginia Early Hearing Detection and Intervention congenital Cytomegalovirus (cCMV) Protocols: VA EHDI is in the process of creating cCMV protocols, in

collaboration with the cCMV workgroup (a subgroup of the VA EHDI Advisory Committee).

5. The Virginia Early Hearing Detection and Intervention Shared Plan of Care: This care coordination was created with input from the VA EHDI Learning Communities (including parents, PCPs, audiologists, hospitals staff, and Early Interventionists). The materials include:
    a. The Shared Plan of Care for Parents
    b. The Shared Plan of Care for Audiologists
    c. The Shared Plan of Care for Early Intervention
    d. The Shared Plan of Care for Primary Care Providers
6. What Is My Baby Hearing?: A prenatal fact sheet developed in 2017, in collaboration with Women Infant and Children and Virginia Home Visiting programs.
7. Are You Sure Your Baby Hears…Everything?: A postnatal fact sheet developed in 2017, in collaboration with Women Infant and Children and Virginia Home Visiting programs.
8. Engaging Parents in System Design to Reduce Loss to Follow-Up: published in the Journal of Early Hearing Detection & Intervention (Nov. 2018).
9. Virginia Immunization Information System Newsletter: An overview of Virginia Early Hearing Detection and Intervention Program to provide education for Primary Care Providers; published July-Sept 2018 edition.
10. The Virginia Early Hearing Detection and Intervention Program biteable video: VA EHDI developed in collaboration with VDH Communications team to provide education on hearing screening (2018).
11. The Virginia Early Hearing Detection and Intervention Program Learning Community biteable video: An Overview of the VA EHDI learning communities developed in collaboration with VDH Communications team (2018).
12. VIIS Online Poster: Developed in 2017 in collaboration with the Virginia Infant Immunization Program, to educate primary care providers.
13. VIIS Online Provider Video: Developed in 2017 to provide Primary Care Providers information on Early Hearing Screening.

Previous Work of a Similar Nature:

The VA EHDI has successfully completed numerous projects and activities of a similar nature to TESA. Specifically, the program was awarded and has successfully managed:

- A series of HRSA Maternal Child Health Block (MCHB) grants related to hearing screening from 2001 – 2019, to include implementation of a Learning Collaborative for quality improvement; and
- A series of CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) cooperative agreements related to birth defects prevention and surveillance, and EHDI tracking, surveillance, and integration from 2002 to 2019.

ORGANIZATIONAL INFORMATION:

The Virginia Department of Health (VDH) is located in the Secretariat of Health and Human Resources that also includes the Departments of Behavioral Health and Developmental Services, Social Services, and Medical Assistance Services (Medicaid/Child Health Insurance Programs).

Project Narrative

In May 2018, Governor Ralph Northam appointed Dr. M. Norman Oliver to serve as the State Health Commissioner. The Deputy Commissioner for Population Health is Dr. Laurie Forlano.

The mission of the Virginia Department of Health (VDH) is to promote and protect the health of all Virginians. The agency's vision statement is "Become the Healthiest State in the Nation." VDH has completed an agency strategic plan, which includes the agency's vision, objectives and metrics. Agency objectives continue to support and improve the health of all Virginian's through efficient and effective execution of operations and delivery of services. The leadership reviews monthly reports on the agency's progress towards achieving its objectives, with the intent of identifying best practices and helping the agency improve its performance and become the healthiest state in the nation. A data dashboard is available on the internet. Several needs assessments are conducted through local VDH districts of populations within their communities and contribute to the development of health policy through a wide range of analyses and research concerning the cost, quality, and accessibility of healthcare and the magnitude and distribution of health inequities in the Commonwealth.

The Office of Family Health Services (OFHS), under the leadership of Dr. Vanessa Walker Harris, is the largest office in the agency based on the amount of funding received from multiple sources, the number of diverse programs provided, and the numbers of people served. OFHS contains division directors and program staffs committed to a unified effort and integrated approach to maximize resources, minimize duplication of effort, efficiently target overlapping populations, systems and organizations and decrease known disparities. Current program staff are proficient in the core public health competencies, and have experience working within a large public health system and collaborating externally with a diverse network. The Office is composed of four divisions: Child and Family Health (DCFH); Prevention and Health Promotion (DPHP); Community Nutrition (DCN); Population Health Data (DPHD). Administrative support is provided through the Population Health Shared Administrative Services (SAS). OFHS submits, monitors, coordinates, and administers funds received from the Title V MCHB Grant and the Preventive Health and Health Services Block (PHHSB) Grant, as well as approximately 50 categorical grants. While many grants are administered entirely within VDH, others are managed in partnership with other agencies or organizations in order to best meet the goals and objectives of the project. As a result, OFHS manages several hundred contracts and memoranda of agreements.

The Virginia Early Hearing Detection and Intervention Program (VA EHDI) is housed within DCFH alongside other state newborn screening, birth defects surveillance, Children and Youth with Special Health Care Needs (CYSHCN), maternal-child and early childhood and home visiting programs, as well as reproductive and adolescent health initiatives. The Early Child Health Programs Manager is the agency liaison to the Early Intervention Program in the Department of Behavioral Health and Developmental Services, and works with the Early Periodic Screening, Diagnosis, and Treatment program in Medicaid at the Department of Medical Assistance Services. As of May 2019, Jennifer Macdonald has served as the acting director of DCFH and provides oversight, quality assurance and direction to ensure an integrated approach amongst unit leads who, in turn, provide oversight, foster coordination and collaborative approaches among staff and programs in the division.

Close and supportive partnerships and collaboration exists between VA EHDI and Community Nutrition-WIC, and DPHD within OFHS and the Population Health SAS. DPHD provides consultation, technical assistance, and analysis for maternal and child health policy, epidemiology, and surveillance, including such support for the VA EHDI. The Population Health SAS is responsible for fiscal operations, procurement and contracting, human resource management, grants administration, and general administration. This Division has a close working relationship with the Agency's administrative offices (Fiscal, Budget, Purchasing and General Services, Internal Audit, Human Resources). This infrastructure ensures that programs are managed in compliance with federal and state policies and regulations.

Other key internal agency partners include Division of Immunization within the Office of Epidemiology and Office of Information Management (OIM). Examples of collaboration include data sharing with the Virginia Immunization Information System (VIIS) and maintenance of the VISITS, VA EHDI's sole data application.

OFHS applies a health equity lens to grant implementation and seeks appropriate consultation from the Office of Health Equity (OHE) within the VDH. The OHE's mission is to identify health disparities, their root causes, and promote equitable opportunities to be healthy. The core value of their work focuses on data analysis and research that defines the distribution of health, disease, and social determinants of health and identifies high priority target areas. They advance health equity by promoting access to quality health care and healthy public policy and engaging communities to support these efforts.

VA EHDI team includes Daphne Miller, EDHI Coordinator, Supervisor and Principal Investigator of this funding opportunity; Deepali Sanghani, Follow-up Coordinator; Antoinette Vaughan, Follow-up Specialist (FT); Jennie Dinh, Program Administrative (FT); Project Coordinator (FT/vacant); cCMV Coordinator (FT/vacant). This staff will transition some its current follow-up activities to those more aligned with this grant work plan. Using the web-based reporting system VISITS, linked to the electronic birth record, staff will continue to provide timely follow-up , monitor loss to follow up/documentation at all stages of the EHDI process as well as monitor follow-up services such as Part C-EI enrollment and family support.

The VA EHDI is also supported by an Advisory Committee, established in the *Code of Virginia*. The Advisory Committee has been in existence since 1999 and is comprised of a wide range of active participants that have been mandated in this funding opportunity. A small expansion of the membership will be needed to meet funding requirements.

VA EHDI is well positioned to garner necessary support to continue the program's engagement with key stakeholders that are already in place and expand other collaborations to facilitate the requirements of this funding opportunity.

See Attachment 5 for an Organizational Chart