

## PROJECT ABSTRACT

**Project Title:** The EHDI System in Maryland: Reaching Beyond Early Hearing Detection

**Applicant Name:** Office for Genetics and People with Special Health Care Needs, Prevention and Health Promotion Administration, Maryland Department of Health, 201 W. Preston St., Baltimore, MD 21201-2301

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**Problem:** There is a need to increase the number of infants who are identified as deaf or hard of hearing (DHH) by 3 months of age and to increase the number of DHH infants who are enrolled in early intervention (EI) services by 6 months of age. There is also a need to strengthen the capacity of the Maryland EHDI (MD EHDI) system to provide family support and to engage families with children who are DHH. There is a need for engagement of adults who are DHH throughout the EHDI system. There remains a knowledge gap among physicians regarding EHDI process which contributes to a delay in EI enrollment. MD EHDI will nurture its partnership with the Maryland State Department of Education (MSDE) Part C Program and other stakeholders to improve EI enrollment rates.

**Goals and Objectives:** To continue development of a comprehensive and coordinated statewide EHDI system to ensure that children up to age 3, who are DHH, are receiving appropriate and timely services by: 1) leading MD EHDI in improving outcomes for children who are DHH; 2) increasing health professionals' engagement with and knowledge of the EHDI system; 3) improving coordination of care, access to EI services and language acquisition, and 4) strengthening the capacity of MD EHDI to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI System.

**Methodology:** MD EHDI will partner with the MSDE EI Program and a multidisciplinary advisory committee established during the 2017-2020 grant cycle will be expanded to engage health care professionals, families, and other stakeholders. This committee will assist in the development of a plan to support hearing screening in children up to age 3. The symbiotic partnership with MSDE will allow expanded outreach and education to service providers, while the MD EHDI Program increases outreach to medical providers. MSDE has recently launched an online EI referral system. MD EHDI will aid in educating audiologists and other medical providers who would not typically be on MSDE's training radar, while MSDE will provide entrée into training programs for EI providers. Discussions between MD EHDI and MSDE have shown that this opportunity is ripe for data use agreements, outreach, training and, ultimately, increased enrollment in EI programs. A part-time contractual Family Support Coordinator position will be created to support and engage families of children who are DHH and to connect them with adults who are DHH.

**Coordination:** Partnerships will be strengthened with the MSDE EI Program, Maryland School for the Deaf, Governor's Office of the Deaf and Hard of Hearing, Maryland's Title V-CYSHCN program, the state chapter of the American Academy of Pediatrics, the state Leadership Education in Neurodevelopmental Disabilities Program, and other public and private providers and agencies.

**Evaluation:** Improvements to timely identification and EI enrollment will be assessed using a quality improvement approach. For pediatricians and providers, measures will be assessed to determine increased knowledge of the EHDI process and efficiency of each child's navigation through the process.

**PROJECT NARRATIVE**

**TABLE OF CONTENTS**

Introduction.....3

Needs Assessment.....4

Methodology.....8

Resolution of Challenges.....15

Evaluation and Technical Support Capacity.....17

Organizational Information.....21

## **PROGRAM NARRATIVE**

### **INTRODUCTION**

The statute (Maryland Health-General Article, §13-601) which establishes what is now known as the Maryland Early Hearing Detection and Intervention (MD EHDI) Program within the Maryland Department of Health (MDH) first became effective on July 1, 2000 and was revised in 2014. Associated regulations in section 10.11.02.06 of the Code of Maryland Regulations (COMAR) were revised in 2015. The MD EHDI Program was established within MDH to promote the best language and communication outcomes for children who are deaf or hard of hearing by creating and maintaining systems of care that identify the infant's hearing status and ensure referral to appropriate intervention services at the earliest possible age. The MD EHDI Program is housed in the Office for Genetics and People with Special Health Care Needs (OGPSHCN), which is in turn housed in the Maternal and Child Health Bureau of the MDH Prevention and Health Promotion Administration.

A multidisciplinary advisory council is also governed by the program statute and regulations. The advisory council supports the MD EHDI system by providing information to, consulting with the Program, and by advising MDH to ensure that all newborns receive appropriate, high quality early hearing detection and intervention services. Originally established in 1985 (Chapter 402, Acts of 1985), the Council currently operates in accordance with the Annotated Code of Maryland, Health General Article § 13-603. This statute authorizes the Council to make recommendations for operations of the program and advise MDH on setting program standards, program monitoring and review, and provision of quality assurance for the program.

The MD EHDI Program tracks and monitors the newborn hearing screen status of babies in Maryland and ensures that needed follow-up occurs. Babies who pass the newborn hearing screen are followed if they have risk factors for late onset or progressive hearing loss. The MD EHDI Program collaborates with its valued stakeholders to meet the national 1-3-6 guidelines developed by the Joint Committee on Infant Hearing of the American Academy of Pediatrics (AAP) (JCIH, 2007).

MD EHDI Program staff provide follow-up services by contacting families and staff at hospitals, birthing centers, primary care physician offices and other healthcare facilities to ensure that Maryland babies receive the newborn hearing screen, necessary follow up. Program staff ensures referral to early intervention services for infants who are reported to MD EHDI as deaf or hard of hearing (DHH). Newborn hearing screen and follow up data are entered and maintained in a secure web-based data system, accessible to providers for babies in their care. The MD EHDI Program collaborates with a range of stakeholders to meet the goals of the Maryland EHDI system.

The target population of the MD EHDI Program and for this project includes newborns, infants and young children through age three, their families, and the providers who serve their needs. The project aims to improve MD EHDI's coordinated statewide system of care in ways that lead to improved timeliness for newborn hearing screening, hearing status determination, and enrollment into early intervention. The project additionally aims to provide culturally appropriate family support and adult DHH mentoring services to families of children who are DHH, especially those who are newly identified. The work of this project will provide education and resource information to families, health care providers, and educational providers throughout the

statewide EHDI system. The projected outcomes of this project are improved developmental outcomes for children who are DHH, enhanced provider engagement with and knowledge of the EHDI system, improved access to and utilization of early intervention services, and meaningful family engagement and support by families of children who are deaf or hard of hearing (DHH) and adults who are DHH.

**NEEDS ASSESSMENT**

**Current Level of Performance:** The MD EHDI program is charged with tracking and surveillance of all newborns in the state for hearing loss and for risk factors or later onset hearing loss. The state identifies approximately 95 to 100 infants as DHH each year through MD EHDI, equating to the national average of between 1-2 babies identified as deaf or hard of hearing per every 1,000 babies screened. Data from the calendar year 2017 Centers for Disease Control and Prevention (CDC) EHDI Hearing Screening and Follow-Up Survey (HSFS) are used as baseline data for this project and to describe the MD EHDI Program’s current level of performance.

Table 1 shows the percent of newborns screened for hearing by one month of age for calendar years 2015-2017. For calendar year 2017, 99.16% of Maryland newborns received hearing screening and 98.13% received screenings before 1 month of age, indicating that the goal of meeting the first milestone of the 1-3-6 protocol has been achieved. In 2017, of the 974 infants who missed or did not pass their screening, 119 were unable to be contacted or had parents who were contacted but chose not to follow up resulting in a lost to follow up rate of 12.22%.

**Table 1. Percentage of Newborns in Maryland who have been Screened by One Month of Age (includes inpatient and outpatient screening).** *Data source: MD EHDI Program Data*

Year	2015	2016	2017
Percent	98.17%	98.24%	98.13%

For calendar year 2017, MD EHDI achieved a 98% rate for newborn hearing screens conducted by one month of age. Guidance for this submission requests the percent of infants that completed a diagnostic audiological evaluation no later than 3 months of age. For calendar year 2017, this value is 73%, which specifically refers to the number of infants who received a diagnostic evaluation no later than 3 months of age; it does not refer to a conclusive diagnosis. While 73% of infants received at least one diagnostic evaluation by 3 months of age, this measure does not mean that all 73% of those infants received a conclusive diagnosis of their hearing status at the time of the reported diagnostic evaluation. Data that is similarly reported on the CDC EHDI HSFS differs in the following manner: The CDC guidance defines the total number diagnosed as the total number of infants who did not pass a hearing screening and had a documented diagnosis following an audiological diagnostic evaluation/testing; this number is achieved by calculating the total number of babies diagnosed before 3 months (less than 91 days of age) divided by the total number of infants that did not pass the hearing screen. Using the CDC definition, 55.85% of the infants that did not pass the hearing screen were diagnosed before 3 months of age. Of those diagnosed, 100% were referred to early intervention after identification as deaf or hard of hearing. 60.87% were enrolled in early intervention Part C program by 6 months of age.

As of October 28, 2019, 138 infants and toddlers born between 2016 to the present who were identified as DHH as a primary disability are receiving services through Maryland’s Part C program (Maryland State Department of Education data, 2019). It is important to note that this information does not capture all children aged 0 to 3 years who are DHH and served through Part

C during this time period. This data only reflects those with a primary diagnosis of hearing loss. Other children who may have other diagnoses as a primary disability but also have hearing loss are not likely to be included in these data.

**Population Needs:** Maryland is a small but diverse state comprised of 24 jurisdictions, including 23 counties and the city of Baltimore. With an estimated population of more than 6 million in 2018, Maryland is the nation’s 19th most populous state, yet ranks as the ninth smallest state according to land area. Although a small state in size and population, Maryland has great geographic diversity. Geographic “barriers” often create special challenges in the procurement of health care services due to lack of access (transportation and distance), lack of providers and lack of specialty care. Maryland’s Maternal and Child Health (MCH) population includes an estimated 1.2 million women of childbearing age (ages 15-45), 1.5 million children and adolescents (ages 0-19), and 386,422 young adults in 2015. An estimated 250,000 Maryland children and youth (ages 0-17) have special health care needs.

Tables 2 and 3 present a regional analysis of the number of births and referrals to Maryland’s Part C program in 2017. There is a large regional variation between jurisdictions in the number of children served. Some jurisdictions serve a much greater proportion of children who have hearing loss in the state than others. For example, Frederick County, Prince George’s County, Baltimore County and Baltimore City, Howard County and Montgomery County have the highest number of children who are DHH identified through the MD EHDI Program from 2016 to present (see table below). Frederick County and Howard County serve as home to the two campuses of the Maryland School for the Deaf, which serves children ages birth to 21 years and ranks as having the highest number of children who are DHH identified through MD EHDI from 2016 to present. Many families with a child who is DHH move to certain jurisdictions within the state, such as Frederick County, which offers relatively more services for children who are DHH. Other jurisdictions, such as those counties on Maryland’s rural Eastern Shore or far western Maryland where the prevalence of childhood deafness and hearing loss is low, have very limited services available to children who are DHH.

**Table 2. Number of Births and Referrals to Infants and Toddlers Services in Maryland by Region, calendar year 2017.** *Data source: MD EHDI Program Data (includes late onset)*

Maryland region	Total Births	Referred	Enrolled
Capital (Frederick, Montgomery, and Prince George’s Counties)	23,798	49	40
Central (Anne Arundel, Baltimore City, Baltimore County, Carroll County, Harford County, and Howard County)	35,031	53	40
Eastern Shore (Queen Anne’s, Talbot, Caroline, Dorchester, Wicomico, Somerset, Worcester, and Cecil Counties)	3,604	12	11
Southern (Calvert, Charles, and St. Mary’s Counties)	2,710	4	4
Western (Garrett, Allegany, and Washington Counties)	3,012	3	1
Total	68,155	121	96

It is not known exactly why jurisdictions who serve relatively few children are not serving more children who are DHH. One possibility is that there are no children with a primary diagnosis of a hearing loss in these counties, as it is a very low-incidence condition; a more likely explanation may be that families of children who are DHH move to other jurisdictions with better services or that there are children living in these counties with hearing loss that have not yet been diagnosed due to the lack of screening and diagnostic services in those areas. The jurisdictions that are serving increasingly greater proportions of children are primarily located in the Central part of the state where the population density is higher and there are far greater services for children who are DHH.

**Table 3. Number of Infants Identified as Deaf or Hard of Hearing (DHH) by Maryland jurisdiction, Calendar Year 2017.** *Data source: MD EHDI Program Data*

Maryland jurisdiction	Number of Infants Identified as DHH	Maryland jurisdiction	Number of Infants Identified as DHH
Anne Arundel County	1	Howard County	12
Baltimore City	10	Kent County	1
Baltimore County	14	Montgomery County	11
Calvert County	1	Prince George's County	21
Carroll County	4	Queen Anne's County	3
Cecil County	4	St. Mary's County	6
Charles County	1	Talbot County	3
Dorchester County	2	Washington County	1
Frederick County	29	Wicomico County	5
Garrett County	2	Worcester County	2
Harford County	4		

*Disparities:* Neither electronic import nor manual entry of race or ethnicity is required by MD EHDI disallowing valid statistical analysis to be conducted on this measure. Information is not collected on gender identity or sexual orientation, however the MD EHDI System works to provide educational and resource materials and presentations in a manner which is culturally sensitive to recipients in ways to include primary language and health literacy. The Maryland Early Hearing Detection and Intervention Advisory Council, MDH leadership, and other EHDI stakeholders are active participants in providing feedback to the MD EHDI Program regarding culturally sensitive, language accessible (to include closed captioned and American Sign Language interpreted materials on websites), and appropriate literacy levels of print materials and presentation content. Additional information on disparities is contained in the methodology section.

**Barriers and Plans to Overcome**

*Barriers to Initial Screening:* With an overall newborn hearing screening rate of 99.16% for calendar year 2017, where 98.13% of infants screened had their screenings before they were 1 month of age, there appear to be few barriers affecting the initial stage of screening. Barriers to initial screenings that continue to be addressed are equipment failure and staff turnover and training needs. Monthly hospital compliance monitoring allows for timely identification of issues that may affect the screening rate. A high number of infants missing or not passing the screening

at any facility prompts the MD EHDI program audiologist to consult with facility staff and provide timely technical assistance.

Not all infants born in Maryland are born at hospitals where they would receive an inpatient newborn hearing screening. According to MD EHDI data, in 2017 there were 258 reported birthing center births and 534 reported home births with a total of 792 out of hospital births. The number of birthing center and home births has been relatively stable over the past three years (2015=791; 2016=768; 2017=792).

While out of hospital births account for a very small percentage of births in the state each year, out of hospital births make up the majority of infants who are never screened. For calendar year 2017, 792 out-of-hospital births were reported to MD EHDI and 23% of those births were not screened for hearing loss. For calendar year 2018, 828 out-of-hospital births were reported to MD EHDI and 21% (174) of those births were not screened for hearing loss. Through the provision of HRSA funds, newborn hearing screening equipment has been purchased and distributed to two of Maryland's three birthing centers, and relevant training has been completed. Continual educational outreach on MD EHDI protocols and training of new staff will remain in place for Maryland's birthing centers. Opportunities will be sought to continue to provide educational information to independent nurse midwives as well.

*Barriers to Outpatient Screening and Outpatient Diagnostic Evaluations:* Transportation is a major factor in whether or not some families can access outpatient screening and diagnostic evaluations. There are several geographic barriers to travel within the state. Educational initiatives targeting families, medical homes and audiologists which reinforce the sense of urgency and developmental implications of not screening for and identifying hearing loss by 3 months of age will continue and be improved upon. Prioritization of screening and diagnostic appointments will be encouraged as well as coordinating audiology appointments with other appointments when possible where travel distance is an issue. The Early Childhood Hearing Outreach (ECHO) Initiative will be established and partnerships will be sought with Early Head Start/Head Start and day care centers to ensure that hearing screenings are made available for children up to age 3. Partnerships with local university audiology programs will be sought as well to engage audiology students in providing screening services. MD EHDI will continue to engage with audiologists from the state LEND program for input and to determine their ability to engage in direct hearing screening of the 0-3 Early Head Start/Head Start and day care population.

*Barriers to Enrollment into Early Intervention Services:* Early intervention services in Maryland are overseen by the Maryland State Department of Education (MSDE). Data sharing has been established between MSDE and MD EHDI under a 2007 multi-agency memorandum of understanding on early intervention. The MD EHDI Program receives updated early intervention data from MSDE on a regular basis. Improvements to the MD EHDI data system have included an early intervention module which allows documentation of early intervention enrollment status and specification of suspected or confirmed hearing loss. MSDE has recently launched an online early intervention referral portal. MD EHDI and MSDE Infants and Toddlers Program staff will work together during this project period to address potential improvements that can be made to the ways in which the data are shared as well as training needs for local Infants and Toddlers staff and other providers who influence the early intervention enrollment process. The work of this project will investigate processes that are occurring at the local early intervention level to promote uniformity of procedures where possible. Detailed data on early intervention referrals

and enrollment would be valuable for strategic planning and problem-solving to ensure optimal enrollment of children who are DHH in early intervention. For calendar year 2017, of those diagnosed, 100% were referred to early intervention after identification as DHH but only 60.87% were enrolled in early intervention Part C program by 6 months of age. It was determined that some were referred more than once. The hiring of a part-time Family Support and Engagement Coordinator whose duties will be tailored to include targeting infants and young children who are in need of referral and enrollment into early intervention services, and who will work with families to determine the reasons for non-referral or non-enrollment is expected to greatly reduce this barrier to care.

## **METHODOLOGY**

The overarching goal of this project is to develop and support a comprehensive and coordinated statewide EHDI system of care to ensure that newborns, infants and young children up to 3 years of age, are receiving appropriate and timely services, including screening, diagnosis, and early intervention to optimize language, literacy, cognitive, social, and emotional development. This will be accomplished by: 1) leading the MD EHDI System of Care in improving outcomes for children who are DHH, 2) increasing health professionals' and service providers' engagement with and knowledge of the EHDI system; 3) improving coordination of care, access to early intervention services and language acquisition, and 4) strengthening the capacity of the MD EHDI System of Care to provide family support and engage families with children who are deaf or hard of hearing (DHH) and adults who are DHH throughout the EHDI System.

The proposed project will incorporate newly solidified partnerships while intentionally building on prior successes in quality improvement and a network of partners and collaborators at the state and regional levels. This will be used to improve the leadership and collaborative infrastructure for EHDI system improvements to, in turn, achieve timely identification and referral of infants who are DHH, and to improve family engagement and leadership in the system of care. The project team has identified four project goals in support of the overarching goal. These goals build upon priorities and strategies identified and developed previously by state and local stakeholders.

This project will allow for the development of modifications of national tools to address the specific needs of Maryland families and providers in the EHDI system. Through partnership, collaboration, family engagement and DHH adult engagement, improved follow up protocols—as well as solutions for current barriers to newborn hearing screening follow up, diagnosis, referral and enrollment in EI services—can be identified and awareness and educational materials created and disseminated.

### **Goal 1: Lead MD EHDI System of Care to improve outcomes for children who are deaf or hard of hearing**

**Objective 1.1:** By Year 1, Quarter 2 expand on and support existing EHDI Screening and Beyond Advisory Committee to include broad representation of stakeholder groups that will guide the efforts to improve developmental outcomes of children who are DHH and the implementation of project objectives and strategies.

**Objective 1.2:** By Year 1, Quarter 1 and ongoing, provide a coordinated infrastructure to 1) 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 2) reduce loss to follow-up / loss to documentation numbers.

**Objective 1.3:** By Year 2, Quarter 4, Develop and establish a plan to expand the MD EHDI System of Care capacity to support hearing screening in young children up to 3 years of age.

**Screening and Beyond Advisory Committee:** Through previous grant initiatives, the MD EHDI Program established the EHDI “Screening and Beyond” Advisory Committee. The MD EHDI Program additionally has an advisory council with membership requirements established in statute. The EHDI Screening and Beyond Advisory Committee (SBAC) will continue, with the potential for change in membership from the current group. Membership will be updated and representation sought from a broad array of stakeholders, including the Maryland EHDI Advisory Council where appropriate. The proposed membership includes: parents / family members of children who are DHH; Maryland State Department of Education, Maryland Infants and Toddlers Program (State Education Agency: Part C); Maryland Office for Genetics and People with Special Health Care Needs (State Title V CYSHCN Program, MD EHDI Program); Maryland Chapter, American Academy of Pediatrics (State Chapter of American Academy of Pediatrics; primary and subspecialty pediatric providers; EHDI MD AAP Chapter Champion); Governor’s Office for the Deaf and Hard of Hearing (State office of the DHH); Maryland School for the Deaf (State school for DHH); Kennedy Krieger Institute (Maryland Center for Developmental Disabilities; Maryland LEND); Maryland State Department of Education (State Education Agency; School-Age Performance Specialist); Maryland Department of Health (State Health Department; Title V CSHCN; WIC; Home Visiting; Medicaid; Office of Minority Health); The Parents’ Place of Maryland (Parent Organization; Family Voices; F2F Health Information Center; Parent Training and Information Center); Maternal Child Nursing group (Birthing Facilities); Maryland Family Network (provides resources for child care providers as well as parent support centers for high risk families).

Each of the groups represented on the SBAC offers service or expertise essential to one or more parts of the EHDI system. Each organization touches the EHDI process at one or more points in the system. A primary task of the SBAC will be to aid in the development of multiple grant-related plans, including: the formulation and dissemination of a partnership assessment tool aimed at identifying needed partners to address gaps in the EHDI System; development and implementation of a plan to expand the EHDI infrastructure to include hearing screening for children up to age 3; and development and implementation of a plan to address diversity and inclusion in the EHDI System. Using QI methodologies, the SBAC will develop and implement a strategy to monitor and assess program performance in meeting program goals and objectives. The Committee will meet bi-monthly for the first quarter of the project to review the EHDI protocols and make recommendations for changes that will form the basis of Plan-Do-Study-Act (PDSA) cycles for the program. The group will meet quarterly thereafter to review data from these PDSA cycles, as well as to provide oversight of all proposed grant activities.

**Coordinated Infrastructure:** As the leader of the Maryland EHDI System, the MDH EHDI Program takes very seriously its role of providing coordination, opportunities for communication, and referrals to resources for stakeholder throughout the state. The Project Director has, and will continue to conduct state-level outreach and education to stakeholders of the EHDI System (including expectant parents, new parents, providers, home visitors, pediatric

health care providers, and audiologists). Additionally, as part of the Maternal and Child Health Bureau in the Maryland Department of Health, the MD EHDI Program is uniquely positioned to conduct outreach and education to other public health / service programs to enhance awareness of risk factors for DHH and the importance of acknowledging and acting on the concerns of parents and caregivers. The MD Family-to-Family Health Information Center was a previous partner on the HRSA funded EHDI grant from 2017 to 2020, is a grantee of Maryland's Title V CYSHCN program, and remains a strong ally to the EHDI Program. Early Head Start programs around the state are also currently in frequent contact with the EHDI Program and the project will continue and expand upon this contact. Additionally, the Maryland Community of Care Consortium for CYSHCN (Maryland CoC), a broad and diverse group of stakeholders who meet quarterly, is an excellent avenue through which to broadly disseminate information and materials to increase public and provider awareness about the EHDI program and the 1-3-6 guidelines at least annually. Using the broad spectrum of resources available to MD EHDI, including but not limited to, members of the SBAC and the Maryland EHDI Advisory Council, the project plans to solicit feedback on and to update EHDI print and web-based outreach materials for families, public and providers.

The MD EHDI Program and OGPSHCN recognizes the need for concrete plans to identify disparities and incorporate diversity and inclusivity into program planning. The MD EHDI data system has the fields and capacity to capture demographic information such as race or ethnicity through Maryland's health information exchange, but currently receives only a limited amount of these data from birthing hospitals and other reporting sites. A first step in developing a plan will be to assess the feasibility of efforts to increase reporting of race and ethnicity data in connection to newborn hearing screening. Factors impacting data collection will be analyzed and variability of hospital reporting capacity will be considered to inform planning around data collection, with the guiding goal of ensuring that Maryland's EHDI system activities are inclusive of all of Maryland's populations and that disparities are identified and addressed.

An ongoing and current task is to continuously analyze current EHDI protocols and develop PDSA cycles aimed at improving achievement of 1-3-6 guidelines, particularly focused on improving timeliness to diagnoses. Ideally, the SBAC will be able to aid in this effort by assessing whether and what factors impact access to diagnostic evaluations. Based on the SBAC's assessment, as well as MD EHDI internal assessments, the project will develop new follow up protocols, train EHDI follow up staff on new protocols and their rationale, and implement new protocols and collect data on follow up statistics and timely screening, identification, and referral.

A previous project of the MD EHDI Program involved a quality improvement initiative supported through the University of Maryland School of Nursing. Through this initiative handout cards were developed, which included hearing screening results and, for those babies that did not pass, appointment information for free audiology follow up. A component of this grant project will be to determine capability to expand on this previous quality improvement initiative.

**Expand MD EHDI System of Care:** As previously mentioned one task of the SBAC and the project will be to identify ways to expand MD EHDI System of Care capacity to support hearing screening in young children up to 3 years of age, and to develop a concrete plan to do so. In order to identify the needed partnerships and mechanisms for such an expansion, the project will establish connections with other public health / service programs to enhance awareness of risk

factors for DHH and the importance of acknowledging and acting on the concerns of parents and caregivers for older children. Utilizing resources from National Center for Hearing Assessment and Management (EHDI National Technical Resource Center), the project aims to establish the Early Childhood Hearing Outreach (ECHO) Initiative as part of the MD EHDI System of Care to provide early childhood educators and health providers with up-to-date information on recommended hearing screening practices so that children with hearing health needs receive appropriate services. The project will review the tools offered by the ECHO initiative and determine which would be most appropriate and beneficial to educate and inform Maryland stakeholders, and will create outreach and training materials in accordance with ECHO intuitive principles. The project will collaborate with local university program audiology students, the local Hearing and Speech Agency, and community outreach departments of local healthcare facilities to assist with hearing screening in young children up to 3 years of age. Through the continuation of the broadly-based MD EHDI SBAC, provision of a coordinated infrastructure, and expansion of system of care capacity, the project hopes to improve awareness of and engagement in the EHDI process in Maryland.

**Goal 2: Increase health professionals' and service providers' engagement with and knowledge of the EHDI system.**

**Objective 2.1:** By Year 4, Quarter 4, increase healthcare and service provider awareness (as measured by percentage of stakeholders who demonstrate an increase in knowledge and awareness; and number of outreach and education activities conducted) of the EHDI system and the 1-3-6 goals.

**Objective 2.2:** By Year 4, Quarter 4, increase healthcare and service provider awareness of the need for hearing screening up to age 3.

**Objective 2.3:** By Year 4, Quarter 4, increase healthcare and service provider awareness of the benefits of a family-center medical home and the importance of well-coordinated family-professional partnerships (to include the communication of accurate, comprehensive, current, evidence-based information to families to aid in the language acquisition decision-making process).

The project will conduct state-level outreach and education to stakeholders of the EHDI System (expectant parents, new parents, providers, home visitors, pediatric health care providers, audiologists) on the EHDI System and 1-3-6 guidelines. As previously mentioned, the Maryland CoC, a broad and diverse group of stakeholders who meet quarterly, is coordinated out of OGPSHCN and is an excellent avenue through which to broadly disseminate information and materials to increase public and provider awareness about the EHDI program and the 1-3-6 guidelines at least annually. As the project develops and implements plans to expand EHDI System capacity to screening children up to age 3, materials and messaging on the need for hearing screening up to age 3 in state-level outreach and education to stakeholders of the EHDI System and to the Maryland CoC will be incorporated.

Additionally, in collaboration with the EHDI Chapter Champion of the Maryland AAP, the project will conduct grand rounds learning sessions for health care providers on the EHDI system, 1-3-6 guidelines, and the benefits of a family-center medical home and the importance of well-coordinated family-professional partnerships.

Project staff will also explore the creation of less traditional means of messaging, including a multi-part series of learning webinars to provide education to stakeholders. Web-based messaging will be posted on the EHDI page of the MDH website and shared via various social media outlets.

**Goal 3: Improve coordination of care, access to early intervention services and language acquisition for children identified as deaf or hard of hearing.**

**Objective 3.1:** By Y1Q4, utilize quality improvement methodology to review and revise current follow-up protocols with MITP.

**Objective 3.2:** By Y2Q4, strengthen statewide EI programs by building knowledge and skills regarding the EHDI program and the importance of the 1-3-6 guidelines.

**Objective 3.3:** By Y1, Q4, develop needed mechanisms for coordination and data sharing between the MD EHDI program with the Department of Health and the MSDE program.

In order to improve access to early intervention services and language acquisition, MD EHDI and the MITP will conduct a thorough review and analysis of the current EHDI follow-up protocols and implement PDSA cycles aimed at improving achievement of the 1-3-6 guideline, particularly enrollment in to early intervention. The analysis will include a review of the processes in place regarding parent follow-up, documentation, outreach to parents and providers, data review, and referrals with the goal of better understanding the referral process and existing barriers for engaging families in EHDI and early intervention. Based on this analysis, the team will test individual improvement hypotheses over a specific period to identify best ways in which to increase timely referrals and access to early intervention. The results of these PDSA cycles will be reviewed and the successful processes identified will be implemented to improve access to early intervention. The team will develop new follow up protocols based on the results of PDSA cycles. The team will provide training for EHDI staff on the new follow-up protocols and rationale and monitor the implementation for fidelity. Once these new protocols are implemented, data will be collected on timely screening, identification and referral to early intervention.

Working in partnership with MITP, project staff will develop needed mechanisms for coordination and data sharing between MD EHDI and MITP. Currently, data sharing is in place, however, something more may be needed. Together, MD EHDI and MITP will develop a cohesive and mutually beneficial data sharing agreement.

The Maryland State Department of Education developed an online universal referral for pediatric primary care providers to refer children to Part C early intervention services and to be able to track those referrals. Developed by the Center for Technology in Education at Johns Hopkins School of Education, the Community Compass allows a provider to make a referral online, and then track whether or not the referral was processed and accepted or rejected. If the parent/guardian gives permission, it will also allow a provider to find out if a child referred was found eligible for services, and what services are being received. This web-based system was recently completed and released to the public. In collaboration with MITP, the project will conduct state-level outreach and education using print and/or web-based options to stakeholders of the EHDI System (providers, home visitors, pediatric health care providers, audiologists) with a focus on the EHDI system, 1-3-6 guidelines and the newly-launched online referral system for

MITP, while simultaneously conducting outreach to and training with statewide early intervention staff and service providers on the EHDI system and 1-3-6 guidelines.

**Goal 4: Strengthen the capacity of the MD EHDI System of Care to provide family support and engage families with children who are deaf or hard of hearing and adults who are deaf or hard of hearing throughout the EHDI System**

**Objective 4.1:** By Y1, Q2, Establish the Family Support and Engagement Coordinator position within the MD EHDI program.

**Objective 4.2:** By Y2, Q1, Develop and establish a Family-to-Family and DHH Adult-to-Family Support Program to provide support to families with children who are DHH through connections with other families who have children who are DHH and adults who are DHH.

**Objective 4.3:** By Y1, Q2, Develop and maintain active family engagement and leadership efforts in the state EHDI program.

To improve family engagement, partnership, and leadership within the EHDI program, the MD EHDI proposes to create a new position within the MD EHDI Program: Family Support and Engagement Coordinator. This will be a part-time, contractual position aimed at providing family navigation, outreach and support to families of children identified as DHH. This position will ideally be filled by a parent of a child who is DHH. Building on this model of parents helping parents, using materials from the previous grant-funded Parent Connections program, and in conjunction with multiple stakeholder consultant organizations the project proposes to develop a Family-to-Family and DHH Adult-to-Family support program. We know that families with children who are DHH report that the most valuable source of support for them is other families with children who are DHH. Moreover, families with children who are DHH benefit from access to support, mentorship and guidance from adults who are DHH. To provide families with the supports that they need, the project will recruit at least one family member of a DHH child and at least one DHH adult to be trained to provide support, mentorship and guidance to families of children who are newly identified as DHH. The Family Support and Engagement Coordinator will also receive this same training. The project will create a training curriculum for Family-to-Family and DHH Adult-to-Family mentors and conduct the training. A major component of the Family Support and Engagement Coordinator's work will be to determine ways the position's duties can be embedded in the EHDI follow up protocols. The project will determine best methods of connecting families to Family-to-Family and DHH Adult-to-Family mentors, in consideration of state and federal privacy laws. Another major component of the Family Support and Engagement Coordinator's work will be to assist in the development and implementation of plans to address diversity and inclusion in the EHDI system. As what we hope will become a primary source of information for parents around the state, this position is responsible for ensuring that MD EHDI 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. Awareness of disparity considerations will be an essential component of the job description for this position and training and/or technical assistance will be liberally sought to ensure that all activities are inclusive.

For the third objective in Goal 4, the project will build on existing activities and develop new activities to increase family engagement and leadership efforts within the state EHDI program. In

collaboration with other stakeholder organizations, particularly parent support organizations around the state, the project will pursue opportunities for parents to attend activities to increase family engagement and leadership efforts by increasing the number of activities offered, and by expanding the outreach efforts to address the needs of parents in rural areas and in areas that show a high loss to follow up. The EHDI page on the MDH website will be reviewed, updated and expanded as part of the project to provide more valuable and timely information to parents. Project staff will rely on existing partnerships around the state to recruit parents of DHH children to join various leadership trainings. Where applicable, families will be referred to Leadership training around the state, including, but not limited to The Parents' Place of Maryland (Maryland's F2F) Special Education LEADers training, currently held annually, and the upcoming "Serving on Groups that Make Decisions: A Guide for Families," training.

In reviewing materials using the broad spectrum of resources available to MD EHDI, including but not limited to, members of the SBAC and the Maryland EHDI Advisory Council, the project plans to update EHDI print and web-based outreach materials for families, public and providers, reviewing them for accuracy, cultural competency, literacy level and content and to expand and update the EHDI Program webpage on the MDH website. Using these newly developed culturally and linguistically appropriate materials, webinars and trainings will be developed to educate families on the EHDI system, stress the importance of the 1-3-6 EHDI guidelines and educate on the benefits of a family-center medical home and the importance of well-coordinated family-professional partnerships. The Project Team will consider current research, best practices, and personal experience in reviewing current webinars or trainings in existence, identify gaps, and design multiple short webinars/videos to be disseminated using various mechanisms, including through the EHDI Advisory Council, the Maryland CoC, hospitals, obstetric providers, and Maryland AAP, and post them on stakeholder websites.

*Plans for participating in the Annual EHDI Meeting:* Each year of the proposed budget for this project includes a request for funding to cover one EHDI program staff, one parent of a child who is DHH and one Early Intervention/Part C staff to attend the National Early Hearing Detection and Intervention annual meeting. In past years, MD EHDI has successfully funded a parent of a child who is DHH to attend the National EHDI Meeting. These parents have historically become engaged and valued contributors to Maryland's EHDI system, often joining the MD EHDI Advisory Council and assisting with the implementation of project outreach goals.

*Plans to utilize HRSA-funded resources and efforts:* **Family Leadership in Language and Learning (FL3) Center:** The MD EHDI Program plans to utilize the resources provided by and through the FL3 Center to accomplish the mutually shared goals to increase family engagement opportunities and to strengthen family support within the EHDI system to improve outcomes for children who are DHH and their families. MD EHDI staff will participate in FL3 training opportunities and seek technical assistance support offered by FL3, to include web-based resources around language, literacy, social, and emotional development of children who are DHH. The MD EHDI Program will share information about FL3 training opportunities and technical support throughout its network of stakeholders. This project includes the hiring of a part-time Family Support and Engagement Coordinator whose training will include FL3 family leader training. FL3 family leader training will be offered to other stakeholders, in order to increase the EHDI system's capacity to empower families to help ensure the best developmental outcomes for their children who are DHH. Measures will be taken to ensure targeted inclusion of DHH children who are from underrepresented populations.

**EHDI National Technical Resource Center (NTRC):** The MD EHDI Program plans to utilize the resources provided by the NTRC to accomplish mutually shared goals to increase knowledge and use of evidence-based practices to optimize language, literacy, cognitive, social, and emotional development of children who are DHH. The EHDI system in Maryland has historically benefitted from resources provided by the NTRC and looks forward to continuing to do so. MD EHDI Program staff have utilized NTRC web-based resources and NTRC resources have been shared with stakeholders. **Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program:** The MD EHDI Program plans to continue its partnership with the state LEND Program's clinical and leadership pediatric audiology training program. LEND Program audiology representatives have assisted MD EHDI system initiatives through their service as members of the MD EHDI Screening and Beyond Advisory Committee. Through this partnership LEND staff and audiology trainees were able to increase their knowledge of EHDI processes, challenges and 1-3-6 goals. With this knowledge they are better able to provide screening, treatment and follow-up services to infants and young children confirmed to be DHH with autism spectrum disorder and/or other related neurodevelopmental disabilities. This continued partnership will allow further enhancement of the EHDI systems' capacity to increase EI enrollment of infants and children with autism spectrum disorder and/or other neurodevelopmental disabilities who are also DHH. **National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH):** The MD EHDI Program plans to continue to engage with the NRC-PFCMH through its connection with the Maryland Chapter of the AAP. The MD EHDI Program is fortunate to have a dedicated AAP EHDI Chapter Champion who assists with educating Maryland physicians about EHDI process and 1-3-6 goals. The Chapter Champion actively participates in grant initiatives and attends MD EHDI Advisory Council and EHDI Screening and Beyond Committee meetings.

*Plans for Project Sustainability Beyond Federal Funding:* Alternative funding sources for one full-time Follow-Up Coordinator position will be investigated during project years 3 and 4. With anticipated continued cooperation of established partners, the following objectives may be incorporated into statewide EHDI protocols and continued through the existing EHDI program: outreach and education, including for providers in conjunction with the MD EHDI AAP Chapter Champion; collaboration with other public health programs at MDH and sister agencies; collaborative training relationship for MSDE local Infants and Toddlers Program staff; and collaboration with stakeholders to recruit adults who are DHH as parent to parent mentors on a volunteer basis.

**WORK PLAN:** Please see Attachment 1, which contains the project work plan and logic model.

## **RESOLUTION OF CHALLENGES**

Goals 1 and 2: Outreach and education will be conducted for a range of stakeholders, including families, patients, providers, and service programs. This presents a challenge in determining which outreach modalities and venues are highest yield. To address this, opportunities will be sought to incorporate outreach and education into existing efforts wherever possible, for example seeking time during routine training of service providers to discuss EHDI and, where possible, participating in train-the-trainer events. A related challenge is ensuring outreach materials are written with optimal clarity for the target audience and are genuinely culturally competent. This will be addressed by building end-user review and feedback into all outreach materials, and consideration of other methods to ensure cultural competency. The development of a plan to

expand hearing screening in young children up to age 3 will require input from a variety of stakeholders, and identification of high-yield contacts may be a challenge. However, there is considerable overlap between stakeholders for this purpose and general EHDI stakeholders, so input on plan development will be incorporated into outreach and education efforts as appropriate and to the degree possible. In addition, the EHDI Screening and Beyond Advisory Committee will be enlisted to help with plan development; this may likely take the form of a committee workgroup dedicated to gathering input toward plan development. The plan will include establishing partnerships with Early Head Start/Head Start and day care centers to promote on-site hearing screenings and follow services with technical assistance from the Early Childhood Hearing Outreach (ECHO) Initiative. The ECHO Initiative supplies technical assistance via an easily accessible website and training modules. ECHO Initiative web-based resources even include easily adaptable materials that program may modify to support their needs. Resources provided are not limited to screening. Resources include aids to help educate professionals and parents as well. It is understood that to reach the 0-3 population across the state, efforts will span many different partnerships. MD EHDI looks forward to resolving this challenge by partaking of the resources provided by the ECHO initiative for this very purpose. In addition, MD EHDI has learned to utilize quality improvement methodologies to implement small tests of change and then spread successful strategies to a broader population. A target area of the state will be selected to begin implementation of the ECHO Initiative based on needs of the population and the availability of resources, particularly an available and willing partner to conduct the screenings, preferably a local university and/or the Audiology LEND Program.

Goal 3: Maryland's local Infant and Toddlers programs are housed and administered by different departments and agencies across Maryland's 24 local jurisdictions. This, along with demands of busy caseloads for front-line program staff, underscores the need for deliberate proactive planning on how best to engage each local jurisdiction. This planning will be undertaken through the key partnership with MSDE, whose experience with local programs will be invaluable in designing and implementing EHDI-focused education and trainings for local EI providers. Opportunities will be sought to capitalize on existing trainings and educational events, as well as novel approaches to engaging local EI providers and improving data sharing methods. Engaging with MSDE to determine gaps in knowledge and service delivery that affect EI enrollment outcomes will be addressed by direct collaboration with MSDE partners and by co-leading training and outreach efforts for local early intervention providers.

Goal 4: It is important that the Family-to-Family and DHH Adult-to-Family support programs both reflect the diversity of families served and ensure that families are informed of communication modality options in a balanced and welcoming manner. In order to ensure these programs provide high-quality services, reasonable and feasible standards will be established and required to be met before these programs are operational in a given region or jurisdiction. The Family Support and Engagement Coordinator will play a key role in ensuring families have access to neutral and balanced information on communication modalities, and in coordination of multiple participants and contributors to the family support programs. During grant years 1 through 3, a sustainability plan will be determined for these duties; specifically, whether a dedicated position is required for ongoing support or if processes and oversight can be incorporated into the existing structure of the MD EHDI program. Adult mentors who are deaf as well as hard of hearing will be included throughout the project for mentorship and consultation.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

*Program performance evaluation plan:* Program performance will be evaluated by the MD EHDI program in collaboration with the MSDE EI program. The MD EHDI Program Chief will build upon successful use of an online shared progress document that was used during the prior grant period. This method uses real-time updates to work plan activities, which in turn allows gauging of progress on specific elements and overall progress on grant objectives and goals. In-kind support from the EHDI Program Chief will permit weekly assessment of project status, and monthly summary-level progress updates and discussion with the OGPSHCN leadership will allow consistent and predictable assessment of progress. In addition, monthly check-in calls with between the MD EHDI Program Chief and MSDE will facilitate planning and problem-solving beyond the online shared progress document. Updates on project progress will also be provided at quarterly meetings of the Maryland Early Hearing Detection and Intervention Advisory Council, which affords an additional level of accountability for progress. Grant expenditures will be monitored at multiple levels, including by the MD EHDI program, the OGPSHCN fiscal lead, and a separate fiscal team in the Prevention and Health Promotion Administration. This fiscal team prepares quarterly budget projections based on expenditures to date, which are shared electronically and discussed in person during quarterly meetings with office- and administration-level leadership.

Many, but not all, expected outcomes of the funded activities impact measures that are currently compiled and analyzed through monthly MD EHDI statistics reports, or which can be derived from these reports. These reports include counts of infants at each step of the follow up and referral process, and provide a breakdown of EI enrollment status, including but not limited to categories of unable-to-contact and parents-declined. Counts for all measures are provided for the current calendar year to date and the previous calendar year. These monthly reports are reviewed by the MD EHDI program as well as office- and administration-level leadership, and current reports are shared and discussed at meetings of the Maryland Early Hearing Detection and Intervention Advisory Council.

*Measures to assess performance and progress:* To evaluate project goals and objectives, both a process evaluation and an outcome evaluation will be conducted. The process evaluation will document and monitor the implementation of the project strategies (processes) to provide continuous feedback about the quality of implementation and steps for further refinement. The outcome evaluation will provide important impact information about the degree to which project goals are met and their effects. Processes and outcomes will be assessed that are specific to each project goal, and are described in detail below. The data underlying the following measures will be collected continuously by MD EHDI. Existing infrastructure are in place for data collection and monitoring, which will allow progress on performance measures to be included in annual progress reports.

### **Goal 1: Lead MD EHDI System of Care to improve outcomes for children who are deaf or hard of hearing.**

**Process Evaluation:** Utilizing data from the MD EHDI data system, baseline measurements will be established for the number of infants that completed a newborn hearing screen no later than 1 month of age, the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age, the number of infants identified as DHH who are enrolled in EI services no later than 6 months of age, and the number of health professionals and service providers trained

on key aspects of the EHDI Program. A data collection spreadsheet will be created to routinely track each measurement throughout the project period and ultimately its target outcome. Documentation of a range of items will also be performed, including but not limited to: documenting efforts (spreadsheet) and maintain copies of retention and recruitment materials for soliciting members for the existing EHDI Screening and Beyond Advisory Committee; document current follow-up protocols and modifications made to protocols based on results of PDSAs and other project findings; documenting training efforts for EHDI follow-up staff on new protocols; documenting efforts to expand dissemination of previously developed hearing screening results hospital cards for families of newborns; and document efforts to develop training materials for audiology technicians who perform screening on infants and for medical providers.

Tracking spreadsheets will be maintained to document each outreach and educational activity targeting EHDI system stakeholders and public health/service programs staff.

### **Outcome Measures:**

- *Number of infants that completed a newborn hearing screen no later than 1 month of age* [Goal: increase by 1% per year from baseline the by the end of Y4]
- *Number of infants that completed a diagnostic audiological evaluation no later than 3 months of age* [Goal: increase by 10% from baseline the by the end of Y4]
- *Number of infants identified as DHH who are enrolled in Early Intervention (EI) services no later than 6 months of age* [Goal: increase by 15% from baseline the by the end of Y4]

**Outcome Evaluation:** Outcomes will be evaluated by a review of data contained in data collection spreadsheets, related attachments, and CDC EHDI Hearing Screening and Follow-up Survey data.

### **Goal 2: Increase health professionals' and service providers' engagement with and knowledge of the EHDI system.**

Increased health professionals' and service providers' engagement with and knowledge of the EHDI system is intended to help lead to improved outcomes in timely audiological diagnostic evaluation and diagnosis, and enrollment into early intervention services.

**Process Evaluation:** Utilizing data from the MD EHDI data system, baseline measurements will be established for the number of infants that completed a diagnostic audiological evaluation no later than 3 months of age, the number of infants identified as DHH who are enrolled in EI services no later than 6 months of age, and the number of health professionals and service providers trained on key aspects of the EHDI Program. A data collection spreadsheet will be created to routinely track each measurement throughout the project period and ultimately its target outcome. Tracking spreadsheets will be maintained to document each Grand Rounds learning session and other outreach and educational activity targeting health professionals and service providers. Documented items will include attendance, type of provider, geographic location of event, title and number of informational items disseminated, pre- and post-test results to show knowledge level before and after the outreach activity, description of opportunities offered to engage with the MD EHDI system, number of new MD EHDI data system users recruited, and number and content of PDSAs developed. Throughout the project period, for each

newly recruited MD EHDI data system user, tracking of actual usage of the data system will be monitored and documented.

**Outcome Measures:**

- *Number of infants that completed a diagnostic audiological evaluation no later than 3 months of age* [Goal: increase by 10% from baseline the by the end of Y4]
- *Number of infants identified as DHH who are enrolled in Early Intervention (EI) services no later than 6 months of age* [Goal: increase by 15% from baseline the by the end of Y4]
- *Number of health professionals and service providers trained on key aspects of the EHDI Program* [Goal: increase by 10% by the end of Y4]

**Outcome Evaluation:** Outcomes will be evaluated by a review of data contained in data collection spreadsheets, related attachments, and CDC EHDI Hearing Screening and Follow-up Survey data.

**Goal 3: Improve coordination of care, access to early intervention services and language acquisition for children identified as deaf or hard of hearing.**

**Process Evaluation:** Utilizing data from the MD EHDI data system, baseline measurements will be established for the number of infants identified as DHH who are enrolled in EI services no later than 6 months of age and for the number of health professionals and service providers trained on key aspects of the EHDI Program. A data collection spreadsheet will be created to routinely track each measurement throughout the project period and ultimately its target outcome. Tracking spreadsheets will be maintained to document outreach and educational activities for health professionals and service providers in the manner as described for Goal 2.

**Outcome Measures:**

- *Number of infants identified as DHH who are enrolled in Early Intervention (EI) services no later than 6 months of age* [Goal: increase by 15% from baseline the by the end of Y4]
- *Number of health professionals and service providers trained on key aspects of the EHDI Program* [Goal: increase by 10% by the end of Y4]

**Outcome Evaluation:** Outcomes will be evaluated by a review of data contained in data collection spreadsheets, related attachments, and CDC EHDI Hearing Screening and Follow-up Survey data.

**Goal 4: Strengthen the capacity of the MD EHDI System of Care to provide family support and engage families with children who are deaf or hard of hearing and adults who are deaf or hard of hearing throughout the EHDI System.**

**Process Evaluation:** Baseline measurements will be established for the number of families enrolled in family-to-family support services by no later than 6 months and for the number of families enrolled in DHH adult-to-family support services by no later than 9 months. These baseline measurements will be established by creating and disseminating electronic surveys to local jurisdiction family-to-family support services, DHH adult mentor groups, Governor's Office of the Deaf and Hard of Hearing, Maryland Chapter of AG Bell, and other agencies to determine their enrollment numbers and to inquire about other available providers of these services, and by direct outreach to families of infants within the target age group to determine

their current enrollment status. A data collection spreadsheet will be created and maintained to track enrollment status, geographic area, age of infant, reason for non-enrollment if applicable, measurement throughout the project period and ultimately its target outcome.

**Outcome Measures:**

- *Number of families enrolled in family-to-family support services by no later than 6 months of age* [Goal: increase by 20% from baseline the by the end of Y4]
- *Number of families enrolled in DHH adult-to-family support services by no later than 9 months of age* [Goal: increase by 10% by the end of Y4]

**Outcome Evaluation:** Outcomes will be evaluated by a review of data contained in data collection spreadsheets and related attachments.

*Supporting systems and processes:* Performance outcomes will be tracked through the synergistic use of the online shared progress document and spreadsheets described above, and data available through the secure web-based MD EHDI data system. This data system has been built and tailored to serve the needs of the MD EHDI program, and captures data relevant to both performance measures and outcome measures. This system houses all MD EHDI data for determination of key metrics such as loss to follow up / documentation rate and 1-3-6 guideline achievement, and is structured in a manner that permits new metrics to be derived and analyzed without requiring programming changes. Notably, this system also houses a significant level of data with direct relevance to the follow-up activities conducted by the MD EHDI program's Follow-Up Coordinators, which represent core functions of the MD EHDI program and which will be the focus of quality improvement efforts. The MD EHDI data system also receives EI data from MSDE, and is thus well-suited to serve as a destination of refined and/or new EI data if such changes are identified and implemented to benefit the project. Data mining and analyses are performed by the MD EHDI Program Audiologist, who brings a high level of skill in extracting data and identifying system capabilities. Taken together, performance oversight and monitoring by the MD EHDI Program Chief and data-based analytic services by the Program Audiologist will provide a solid foundation for effective performance evaluation, and is enhanced by the clinical audiology background of both of these key personnel.

*Current experience, skills, and knowledge:* The MD EHDI Program Chief and OGPSHCN Deputy Director have significant and in-depth experience with prior EHDI-focused grants, including the most recent iteration of this grant program. In addition, the OGPSHCN Deputy Director brings extensive family perspective expertise that has been utilized in local, State, and national projects. The MD EHDI Program also has experience administering the Parent Connections Program, which provided families of newly-identified DHH infants with connections to other families of children who are DHH. The goals of the Parent Connections program are fully aligned with several elements of the proposed project, and lessons learned from suboptimal use of the Parent Connections Program by families will be valuable for planning and implementation of the family support activities in this project.

*Data collection strategy:* Data for each measure will be collected using various sources and formats. The MD EHDI data system will be the source of much of the data collected. Spreadsheets will be created and maintained for collecting and tracking data on screening, diagnostic outcomes and EI enrollment. The data will be analyzed throughout the project to

determine if positive change is occurring. Adjustments to methodologies will be made as indicated by findings revealed through data analysis.

*Potential obstacles:* The establishment of the Family Support and Engagement Coordinator position within the MD EHDI Program, along with the attendant duty to coordinate with a range of stakeholders to provide families the optimal resources and experience, may require a fairly high level of oversight, particularly during year 1. This level of oversight could be an obstacle to program performance evaluation activities; however, the programmatic and budgetary elements of performance evaluation described above are already established and will serve to ensure performance evaluation proceeds as planned and that an appropriate balance is achieved between competing demands for the grant activities and other MD EHDI activities, and OGPSHCN has significant capacity for as-needed technical assistance and support around family support and engagement. These factors are expected to help program performance evaluation progress as planned, and also promote the success of the new Family Support and Engagement Coordinator position. Another potential obstacle to program performance evaluation is limitations of the MD EHDI data system that cannot be addressed without changes to its structure. This will be addressed through proactive inclusion of the MD EHDI Program Audiologist, and the database vendor as needed, in development and design of performance evaluation measures that are possible using the existing structure of the data system.

## **ORGANIZATIONAL INFORMATION**

The project partners include the MD EHDI Program and its parent office, the MDH Office for Genetics and People with Special Health Care Needs (OGPSHCN), serving as project applicant, and the Maryland Infants and Toddlers Program (MITP) of the Maryland State Department of Education. The project partners have extensive experience working to support Maryland's population who is DHH and look forward to expanding and enhancing collaborative efforts. MD EHDI will be responsible for directing and conducting the majority of project activities; OGPSHCN will be primarily responsible for fiscal management of the grant, in concert with a fiscal team from the administration housing OGPSHCN, and will share responsibility for project evaluation activities. MITP will collaborate on activities specific to enrollment into early intervention services and the elements included therein. The proposed project will be monitored by multiple levels of programmatic and fiscal oversight to ensure the approved plan is followed and expenditures are actively and accurately tracked. This includes monthly meetings with leadership of the MDH Prevention and Health Promotion Administration, which houses OGPSHCN, and quarterly budget meetings with administration leadership and the administration's fiscal team. These processes will support a high level of accountability and are complemented by existing documentation practices to ensure a clear record of fund management.

**The Maryland Early Hearing Detection and Intervention (MD EHDI) Program:** MD EHDI is part of OGPSHCN within MDH. The program has historically been funded through the Title V MCHB block grant and supplemental grants from HRSA and CDC. MD EHDI has significant experience building partnerships with families, health professionals, and service providers and engaging these stakeholders in a meaningful way, and is well-qualified to direct and conduct the activities outlined in this grant proposal. MD EHDI is currently staffed with four full-time, permanent employees: a director, a program audiologist and two full-time follow-up coordinators. MD EHDI staffs Maryland's Early Hearing Detection and Intervention Advisory

Council, which meets quarterly. The Council is mandated by legislation and currently operates in accordance with the Annotated Code of Maryland, Health General Article § 13-603. Council members, who are drawn from a broad stakeholder community, provide consultation and guidance to the program in its operation and delivery of services. This consultation and guidance, and the connections it facilitates, combined with direct contact from community-level stakeholders, allows MD EHDI to gauge community-level needs and use that information to inform ongoing planning to optimize MD EHDI services.

**The Office for Genetics and People with Special Health Care Needs (OGPSHCN):**

OGPSHCN is housed in the Maternal and Child Health Bureau within the MDH Prevention and Health Promotion Administration and administers the Maryland Title V CYSHCN Program. OGPSHCN's mission is to promote and improve the coordination of a comprehensive, culturally effective and consumer-friendly system of care through strengthening the infrastructure and improving the capacity of these systems; and to continuously evaluate their effectiveness in order to improve the health and wellbeing of CYSHCN in Maryland. OGPSHCN has 19 employees and an operating budget of over \$5 million, about 80% of which comes from federal funds through the Title V Block grant. The OGPSHCN encompasses several different programs that serve children and families throughout the state, including the Early Hearing Detection and Intervention Program; Systems Development Program; Children's Medical Services; Newborn Screening Follow-Up Program; Sickle Cell Disease Follow-Up Program; and Birth Defects Reporting and Information System. The OGPSHCN is well-qualified to direct the fiscal management of the grant as well as project evaluation activities. OGPSHCN staff is comprised of varied professionals including clinicians and public health professional. Staff has extensive experience in program and policy development; data collection and evaluation; and grants and contract management. OGPSHCN has a long history of accomplishments that have positively impacted the health and well-being of CYSHCN and their families in Maryland, as well as ongoing collaboration and partnerships with numerous public and private agencies provide mechanisms that facilitate implementation of OGPSHCN services and activities.

**The Maryland Infants and Toddlers Program:** MITP is part of the Maryland State Department of Education. The Program directs a family-centered system of early intervention services for young children with developmental delays and disabilities, and their families. By recognizing each family's concerns and priorities and focusing on each child's strengths and needs, the MITP assists families of children with special needs during the first four years of the child's developmental journey. MITP provides support, information, and coordinated services in community settings. Primary points of contact and collaboration between MD EHDI and MITP will be with Pam Miller, Ed.D. and Marny Helfrich, M. Ed.

Taken together, the above organizational and staffing elements provide a strong foundation for MD EHDI and OGPSHCN to lead the project and fulfill program requirements and expectations. A project organizational chart is included as Attachment 5.