

PROGRAM NARRATIVE

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PROGRAM NARRATIVE

INTRODUCTION

Maryland's 2012 CDC EHDI Survey indicated that 31.34% of infants who missed or failed the in-patient hearing screen were lost to follow-up or documentation (LTF/LTD). This percentage includes babies who were completely lost to contact as well as babies who had at least one documented contact and no less than three total attempts to facilitate completion of the 1-3-6 protocol process before efforts were directed to other cases.

A definitive birth hearing screen result is the first step in setting the course for hearing status confirmation by 3 months of age and initiation of early intervention services by 6 months of age for babies who receive a diagnosis of a confirmed permanent hearing loss. Children with hearing loss who receive appropriate intervention by 6 months of age are likely to be mainstreamed and not require special education services.¹ They also demonstrate significantly better language than those identified after 6 months of age.

This funding opportunity will allow Maryland to develop and implement specific, targeted efforts reduce the LTF/LTD rate from 31.34% to less than 20% by the end of the of the project period. A comprehensive needs assessment has determined that the majority of the LTF/D babies reside in Baltimore City, Baltimore County and Prince George's County, so efforts in Year 1 one the project will be limited to these geographic regions. The program will continue to staff two full-time follow-up hearing screening coordinator positions and will add an outreach coordinator to work directly with medical home providers in the targeted communities. The two follow-up hearing screening coordinators will continue to follow up with families and providers via phone, fax, mail, and email. The new outreach coordinator will conduct face-to-face outreach to providers at their work-sites to implement and institutionalize methods that will promote sustainability, spread, and continuous improvements that will lead to a reduction in the LTF/LTD rate.

NEEDS ASSESSMENT

Maryland's target population for this project includes infants who are lost to documentation/lost to follow-up after they missed or did not pass the newborn hearing screening. The project also targets the parents, caregivers and health care providers of these infants. In considering the needs of this population, the Maryland Early Hearing Detection and Intervention Program (MD EHDI) examined program data as well as data collected on Maryland's maternal and child health population for the Title V Maternal and Child Health Block Grant 2010 Maternal and Child

¹ Joint Committee on Infant Hearing, American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, Directors of Speech and Hearing Programs in State Health and Welfare Agencies. "Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs". PEDIATRICS 106. 4 (2000): 798 -817. Print.

Health (MCH) Needs Assessment.² This has been updated with the most recent available data whenever possible.

A map of Maryland by county/ jurisdiction and region is included for reference. Maryland's population is estimated at 5,773,552 and is ranked as the 19th largest state population in the nation. Maryland's population grew by 9% from 2000 to 2010, slower than the growth rate for the nation as a whole (9.7%) over the same time period. The state covers 9,774 square miles and is the 7th most densely populated state in the nation, with 595 persons per square mile. Maryland has 24 counties/county-equivalents. From 2000 to 2010, nearly half of all of the state's population growth occurred among Hispanics, and the Hispanic population in Maryland more than doubled³.

From 2000 to 2010, the state's poverty rate increased from 7.4% to 9.7%⁴. While the statewide average was well below the national poverty rate of 15.3% in 2010, certain jurisdictions in Maryland have very high poverty rates, well above the national average. The same is true for child poverty rates in Maryland. Maryland's child poverty rate was 13.1% in 2010, up from 10.7% in 2000⁵. Child poverty varies by race/ethnicity and jurisdiction. Maryland counties with the *highest* child poverty rates in 2012 include Baltimore City (33.4%; up from 27% in 2003); Eastern Shore counties including Somerset (35.2%), Dorchester (31.4%), and Wicomico (24.5%); and rural Western Maryland counties including Garrett (21.4%) and Allegany (25.6%). Counties with the *lowest* child poverty rates in the state are found mostly in the Central (Howard, Anne Arundel, and Carroll counties) and Southern (Charles and Calvert counties) Maryland regions. By race/ethnicity, the highest percentage of children in poverty in the state is among black or African American children, with 23% living in poverty in 2012, followed by 17% of Hispanic or Latino children. The lowest rates of child poverty are found among non-Hispanic White children, at 8% in 2012.⁶

Infants

There are approximately 73,000 babies born in the state each year. Table 1 shows the number of births in Maryland in 2012 by race and Hispanic origin. In 2012, there were a total of 72,751 births, the majority of these births were white, non-Hispanic (33,169), with the next largest group being Black births (24,306), followed by Hispanic births (10,201.)

² Title V Maternal and Child Health Block Grant 2010 MCH Needs Assessment available at <https://perfddata.hrsa.gov/mchb/TVISReports/Documents/NeedsAssessments/2011/MD-NeedsAssessment.pdf>.

³ Pew Research Center, Pew Hispanic Center. (2011). *How many Hispanics? Comparing new census counts with the latest census estimates*. Accessed on 2/14/14 from <http://pewhispanic.org/files/reports/139.pdf>
<http://www.marylandpublicschools.org/MSDE/divisions/planningresultstest/2008+-+2009+Student+Publications.htm>

⁴ Poverty and child poverty rates come from the U.S. Census 2010 Small Area Income and Poverty Estimates, available at <http://www.census.gov/did/www/saiepe/index.html>

⁵ Advocates for Children and Youth KIDS COUNT Data Center. Accessed on 2/14/14 from <http://datacenter.kidscount.org/data/tables/4460-children-in-poverty?loc=22&loct=2#detailed/5/3300-3323/false/868,867,133,38,35,14/any/10017,10018>

⁶ Advocates for Children and Youth KIDS COUNT Data Center. Accessed on 2/14/14 from <http://datacenter.kidscount.org/data/tables/44-children-in-poverty-by-race-and-ethnicity?loc=22&loct=2#detailed/2/any/false/868,867,133,38,35/10,11,9,12,1,13,185/324,323>

Table 1. Number of Births, Maryland, 2012	
Race and Hispanic Origin	Number of births in 2012
Total (Includes races categorized as “other”)	72,751*
White, non-Hispanic	33,169
Black, non-Hispanic	24,306
American Indian	164
Asian or Pacific Islander	5,430
Hispanic*	10,201
<i>Source: Maryland Vital Statistics Annual Report 2012</i>	
http://dhmh.maryland.gov/vsa/Documents/12annual.pdf	
*Includes all births to mothers of Hispanic origin of any race	

After increasing during much of the 2000s, birth rates⁷ for all races and ethnic groups declined in Maryland from 2008 (13.7, all races) to 2012 (12.4, all races). Over this time period, birth rates dropped sharply among Hispanic women, from 28 to 19.9. Rates slowed among Black women, from 15.4 to 13.3; and among White women from 12.6 to 11.7. Birth rates continue to be highest for Hispanic women. Maryland birth rates vary by region and jurisdiction. In 2012, Talbot, Kent and Worcester counties on the Eastern Shore had the lowest overall birth rates at 8.4-8.8 per 1,000 population. Baltimore City had the highest overall birth rate at 14.7, with Prince George’s County in the Capital region having the next highest

rate at 13.5. In those jurisdictions, birth rates are far higher among Hispanic women, though they have dropped significantly since 2008 (22.8 in Baltimore City in 2012 – down from 37.3 in 2008; and 21.4 in 2012 in Prince George’s County – down from 28.4 in 2008.)

Infant Hearing Screening and Incidence of Hearing Loss among Maryland Children

MD EHDI is charged with tracking and surveillance of all newborns in the state for hearing loss and risk factors for later onset hearing loss. The state identifies approximately 80 infants with permanent hearing loss each year through MD EHDI, equating to an identification rate of slightly over 1 per 1000 births.

Table 2. Percentage of Newborns in Maryland who have been Screened for Hearing Before Hospital Discharge	
Year	Percent Screened
2005	88.5
2006	89.4
2007	92.5
2008	98.8
2009	98.7
2010	98.4
2011	98.9
2012	99.4
<i>Source: MD EHDI Data</i>	

Table 2 shows the percent of newborn infants screened for hearing prior to hospital discharge. 98.7% of Maryland newborns received hearing screening and most had their screenings before they were 1 month of age. Screening rates have been consistently high for the past five years, with 99.4% of infants screened in 2012.

⁷ Birth rates are reported per 1,000 population. <http://dhmh.maryland.gov/vsa/SitePages/reports.aspx>

Table 3. Selected MD EHDI Indicators in 2009 and 2012

EHDI Indicator	2009	2012
Average age for follow-up of hearing screening	25 days	33 days
Percent of babies who missed their inpatient hearing screening who returned for an outpatient hearing screening	58.5% (1,024 who returned for outpatient screening /1,749 babies missed inpatient hearing screening)	89.3% (411 who returned for outpatient screening /460 babies missed inpatient hearing screening)
Percent of babies who failed their inpatient hearing screening who returned for an outpatient hearing screening	73% (2,084 babies returned for an outpatient screening/2,854 babies failed inpatient hearing screening)	85.3% (1983 babies returned for an outpatient screening /2,325 babies failed inpatient screen)

Table 3 shows a comparison between 2009 and 2012 for certain indicators in Maryland’s EHDI program. It is important to note that the EHDI program faced several challenges during 2012, including understaffing (one follow-up coordinator position was vacant beginning October 1, 2011 and wasn’t filled until September 2012) which resulted in a significant backlog of cases from 2011 as well as placing the burden of that position’s follow-up duties on the remaining staff to complete in addition to their own job duties. These issues have since been resolved. In 2009, the average age for follow-up hearing screening was 25 days; in 2012 this increased to 33 days. This increase is likely due to the increase in the number of babies born at birth centers (as opposed to hospitals) that the program began following when their data became available to the Program thru an agreement with the Vital Statistics Administration. The percent of infants who missed their inpatient (birth) hearing screening and returned for an outpatient hearing screening increased significantly over this three year period, from 58.5% in 2009 to almost 90% in 2012. There was also an increase in the percent of infants who failed their inpatient screening and returned for an outpatient screening (73% in 2009 to 85% in 2012). While this represents an overall improvement in the rates of infants who return for an outpatient screening after missing or failing their inpatient screening, MD EHDI still faces challenges with the number of infants who are lost to follow up or documentation (LTF/D) at this stage of the EHDI process.

Infant Hearing Screening – Lost to Follow Up/Lost to Documentation

For calendar year 2012, Maryland had a screening rate of 99.4% and a screening pass rate of 96%. In this same year, a total of 350⁸ infants were lost to follow up/lost to documentation (LTF/D). Maryland identifies approximately 70 - 90 infants with permanent hearing loss per

⁸ Please note that this number is higher than the number reported by the MD EHDI program to the CDC for this time period. For the purposes of the data analyzed for this grant proposal, we chose a broader definition of lost to follow up (this higher number includes Maryland residents who were born out of state and babies who passed the initial screen but failed a risk monitoring screen/test).

year, and has a total estimated LTF/D rate of approximately 31% (down from 50% in 2011.) While Maryland’s LTF/D rate has decreased by 19 percentage points since 2011, an identification rate of 1.2% coupled with a 31% LTF/D rate means that there are still infants with hearing loss who are not being identified and/or reported to the state.

There are many factors contributing to Maryland’s LTF/D rate. For example, once the infant is discharged from the hospital, it is often difficult to track down and/or make contact with the families of the babies who need further testing. Maryland has a growing number of families living in poverty and without adequate insurance coverage. There are also a large number of border babies⁹, a significant population of non-English speaking families¹⁰, and a large number of families who are very mobile/transient due to their employment with the federal government. In order to gain a better understanding of the population of infants that are LTF/D, Maryland EHDI conducted analyses of LTF/D data from 2012. MD EHDI now receives the state’s Vital Statistics Administration’s (VSA) record of all births in the state. This resolves a prior discrepancy issue of VSA data indicating 1,800 – 3,100 births over the number reported to MD EHDI. The results are discussed below according to several factors, including birth facility, infants’ residence by jurisdiction and zip code, and at which stage of the EHDI process the loss occurred.

Table 4. 2012 Infants Lost to Documentation/Lost to Follow-up by Birth Facility

Birth Facility	2012 Number of Infants LTF/D	% of total Maryland 2012 Infants LTF/D (Total is 322)	2012 Number of Infants LTF/D with “Missed” Birth Screening Outcome	% of total Maryland Infants LTF/D with “Missed” Birth Screening Outcome
Anne Arundel Medical Center	29	9%	1	2.6%
Baltimore Washington Medical Center	3	0.93%	0	0.0%
Calvert Memorial Hospital	3	0.93%	1	2.6%
Carroll Hospital Center	2	0.6%	0	0.0%
Civista Medical Center	1	0.3%	0	0.0%
Franklin Square Hospital Center	13	4%	0	0.0%
Frederick Memorial Hospital	9	2.7%	0	0.0%
Greater Baltimore Medical Center	3	0.93%	1	2.6%
Harbor Hospital Center	20	6.2%	1	2.6%
Holy Cross Hospital	13	4%	1	2.6%

⁹ EHDI Border Babies are infants and children who receive hearing-related services at a facility located in a state other than the state where the infant was born or currently resides.

¹⁰ 5.9% of people aged 5 years and older in Maryland speak English less than “very well” according to 2005-2009 American Community Survey U.S. Census Bureau data.

Birth Facility	2012 Number of Infants LTF/D	% of total Maryland 2012 Infants LTF/D (Total is 322)	2012 Number of Infants LTF/D with “Missed” Birth Screening Outcome	% of total Maryland Infants LTF/D with “Missed” Birth Screening Outcome
Howard County General Hospital	1	0.3%	0	0.0%
Johns Hopkins Bayview Medical Center	15	4.7%	0	0.0%
Johns Hopkins Hospital	13	4%	2	5.1%
Laurel Regional Hospital	3	0.93%	2	5.1%
Maryland General Hospital	5	1.6%	1	2.6%
Memorial Hospital at Easton/Shore Health	10	3.1%	0	0.0%
Mercy Medical Center	18	5.6%	1	2.6%
Meritus Medical Center	17	5.3%	1	2.6%
Montgomery General Hospital	3	0.93%	0	0.0%
Peninsula Regional Medical Center	2	0.6%	0	0.0%
Prince George’s Hospital Center	49	15.2%	4	10.3%
Shady Grove Adventist Hospital	6	1.9%	1	2.6%
Sinai Hospital	15	4.7%	7	17.9%
Southern Maryland Hospital Center	5	1.6%	1	2.6%
Special Beginnings Birth Center	1	0.3%	1	2.6%
St. Agnes Hospital	5	1.6%	3	7.7%
St. Joseph’s Hospital	3	0.93%	1	2.6%
Union Hospital of Cecil County	19	5.9%	2	5.1%
University of Maryland Medical System	15	4.7%	3	7.7%
Upper Chesapeake Medical Center	13	4%	1	2.6%
Walter Reed National Military Medical Center	2	0.6%	2	5.1%
Washington Adventist Hospital	4	1.2%	0	0.0%
Western Maryland	2	0.6%	1	2.6%

Birth Facility	2012 Number of Infants LTF/D	% of total Maryland 2012 Infants LTF/D (Total is 322)	2012 Number of Infants LTF/D with “Missed” Birth Screening Outcome	% of total Maryland Infants LTF/D with “Missed” Birth Screening Outcome
Regional Medical Center				
Totals	322		39	

Table 4 shows the number and percent of infants who are LTF/D at the screening and diagnosis stages (combined) by birth facility, and also shows the number and percent of infants LTF/D at the screening stage only, in 2012. The majority of infants LTF/D are born at certain facilities (highlighted in the Table), including Anne Arundel Medical Center in Anne Arundel County; Harbor Hospital Center, Johns Hopkins Bayview, Mercy Medical Center, Sinai Hospital, St. Agnes Hospital, and University of Maryland Medical System in Baltimore City; Meritus Medical Center in Washington County; Prince George’s Hospital in Prince George’s County; Union Hospital in Cecil County; and Upper Chesapeake Medical Center in Harford County. Prince George’s Hospital was the birth facility for over 15% of LTF/D infants at the screening and diagnosis stages, and over 10% of infants lost at the screening stage only. Sinai Hospital had almost 18% of infants lost at the screening stage only.

Table 5. 2012 Infants Lost to Documentation/Lost to Follow-up By County

County	2012 Number of Infants LTD/LTF in County	% of total Maryland 2012 Infants LTD/LTF in County
Allegany County	2	0.6%
Anne Arundel	36	11.2%
Baltimore City	68	21.1%
Baltimore County	31	9.6%
Calvert County	4	1.2%
Caroline County	5	1.6%
Carroll County	7	2.2%
Cecil County	22	6.8%
Charles County	4	1.2%
Dorchester County	3	0.9%
Frederick County	9	2.8%
Harford County	15	4.7%
Howard County	6	1.9%
Montgomery County	19	5.9%
Prince George's County	65	20.2%

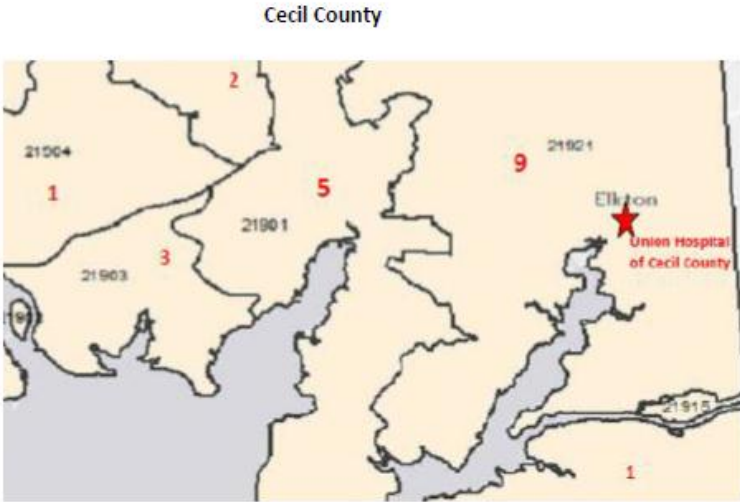
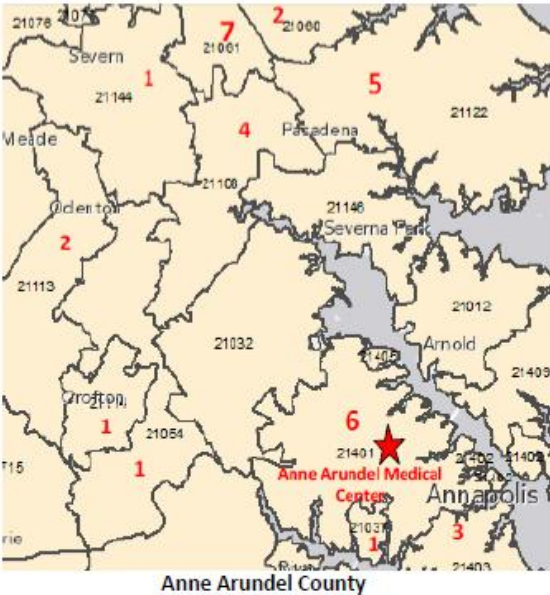
Queen Anne's County	4	1.2%
St. Mary's County	1	0.3%
Washington County	17	5.3%
Wicomico County	2	0.6%
Worcester County	2	0.6%
Totals	322	100.0%

Table 5 shows the number and percent of infants who are LTF/D at the screening and diagnosis (combined) stages by county for 2012. The majority of infants LTF/D reside in certain

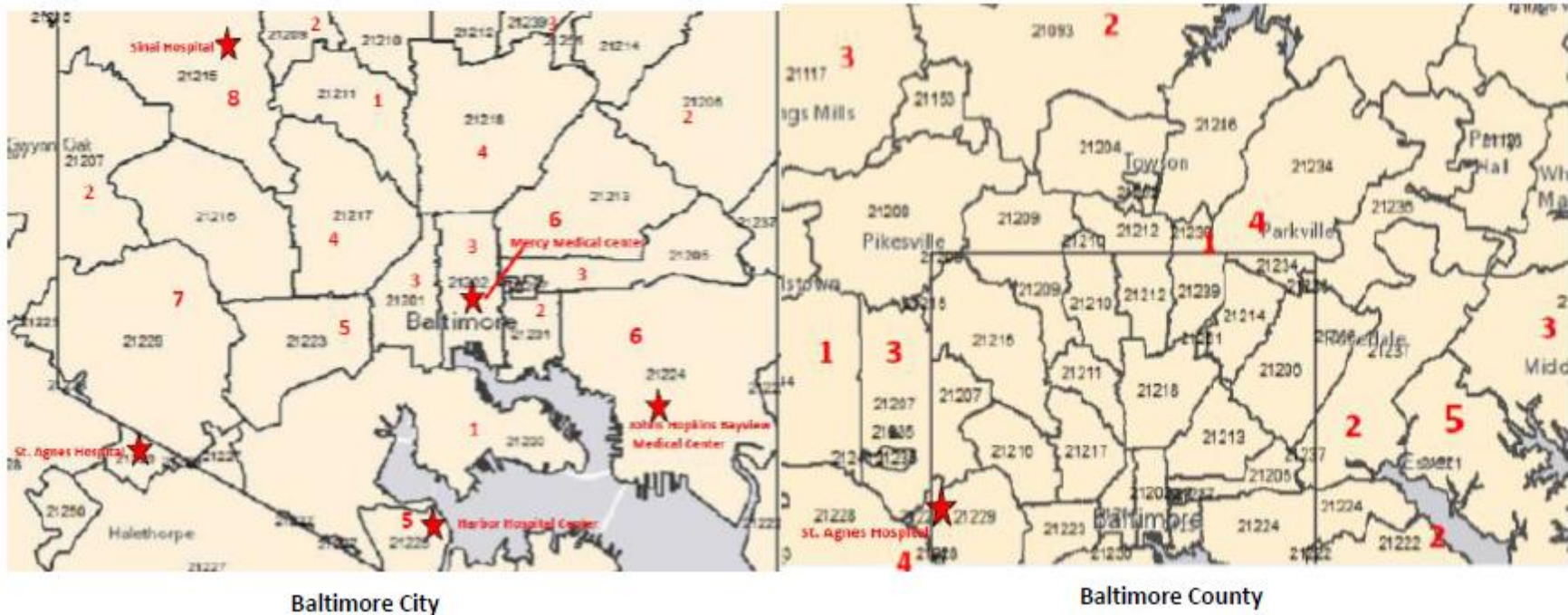
counties (highlighted in the Table), with the highest percentages in Baltimore City (21.1%) and Prince George's County (20.2%). Anne Arundel County had 11.2% of LTF/D infants in 2012, Baltimore County had 9.6%, and Cecil County had almost 7%. Those jurisdictions together accounted for almost 70% of LTF/D infants in the state in 2012. It should be noted that these jurisdictions are among the most densely populated in the state and it is therefore not surprising that most of the LTF/D cases are found there. LTF/D data were analyzed by county and zip code of residence for Anne Arundel, Baltimore, Cecil, Prince George's counties and Baltimore City. In order to gain a better understanding of the locational spread of the LTF/D cases in those counties, the number of cases was mapped by county/zip code and birth facilities with high numbers of LTF/D infants from Table 4 were included (see Figure 1.)

LTF/D cases are spread out over many zip codes in some jurisdictions, such as Baltimore City and Baltimore and Prince George's counties. The 21221 zip code in Baltimore County does contain more cases than any other zip code in the county (16.1%). Two zip codes in Anne Arundel County contain many of the county's cases – 21061 has almost one-fifth of the cases and 21401 has over 16%. Cecil County, which is less populated than the other four counties being analyzed here, has a strong concentration of cases in 21921 (40.9%) and 21901 (22.7%).

Figure 1: 2012 Loss to Follow Up/Documentation Cases by Zip Code and Location of Birth Facilities for Selected Counties



Prince George's County



When examined by map, Anne Arundel County’s cases seem concentrated mostly in the northern zip codes, and to a lesser extent in the zip code where Anne Arundel Medical Center is, and neighboring zip codes. In Cecil County, the city of Elkton is located in zip code 21921, where the majority of cases in that county are found. A neighboring zip code, 21901, has a lot of the county’s cases. In Prince George’s County, most of the LTF/D cases are located in zip codes that border (or are close to) Washington, D.C. As mentioned earlier, Baltimore City’s cases are spread out over many zip codes – however 15 cases (or 22% of those in the City) are in zip codes that contain or surround Sinai Hospital. Baltimore County’s cases are spread around the county, with a higher concentration found in those zip codes bordering or close to Baltimore City.

1-3-6/Loss at Screening, Loss at Diagnosis, Loss at Entry to Early Intervention Analysis

Table 6. 2012 Infants Lost to Follow-Up/Documentation by EHDI Stage

# Infants Lost at Screening (% of total)	# Infants Lost at Diagnosis (% of total)	# Infants Lost at Entry to Early Intervention (% of total)	Total Lost
36 (10.3%)	286 (81.7%)	28 (8.0%)	350

It is clear from Table 6 above that the majority of infants LTF/D are lost at diagnosis (81.7%). It is important to note that Maryland uses a two-screen protocol, so approximately half of these infants would have been recommended for a second screening rather than for a diagnostic evaluation. These infants are defined as lost at diagnosis because they had at least one screen. Slightly over 10% are lost at the screening stage, and 8% are lost at entry to early intervention. We know from the aforementioned spatial analysis that the majority of infants LTF/D are reside in certain jurisdictions – Baltimore City; and Anne Arundel, Baltimore, Cecil, and Prince George’s counties; and that within those counties there are certain zip codes/areas in which these infants are clustered.

Table 7. 2012 Infants LTF/D at Screening by Birth Facility (only birth facilities that had one or more appear here)

Birth Facility	#	%
Calvert Memorial Hospital	1	2.8%
Greater Baltimore Medical Center	1	2.8%
Harbor Hospital Center	1	2.8%
Johns Hopkins Hospital	2	5.6%
Laurel Regional Hospital	2	5.6%
Maryland General Hospital	1	2.8%
Mercy Medical Center	1	2.8%
Prince George’s Hospital Center	4	11.1%
Shady Grove Adventist Hospital	1	2.8%
Sinai Hospital	7	19.4%
Southern Maryland Hospital Center	1	2.8%
Special Beginnings Birth Center	1	2.8%
St. Agnes Hospital	3	8.3%
St. Joseph’s Hospital	1	2.8%
Union Hospital of Cecil County	2	5.6%
University of Maryland Medical System	3	8.3%
Upper Chesapeake Medical Center	1	2.8%
Walter Reed National Military Medical	2	5.6%

Center		
Western Maryland Regional Medical Center	1	2.8%

Table 7 shows LTF/D cases lost at the screening stage only by birth facility. This differs from Table 4 above because Table 7 only includes LTF/D cases that were lost at the screening stage, whereas Table 4 also included cases lost at the diagnosis stage. Table 7 shows us that at the screening stage, the birth facilities with the highest numbers of LTF/D cases are Sinai Hospital (7 cases, or 19.4%), Prince George’s Hospital (4 cases, 11.1%), and St. Agnes Hospital and University of Maryland Medical System (each with 3 cases, 8.3%).

The smallest percentage of LTF/D infants are lost at the entry to early intervention stage (8%). MD EHDI is now receiving early intervention data from the state department of education and as a result has ascertained that babies that the program used to consider referred (as documented by the audiologist who says they informed the parent) were not actually referred because the audiologist did not also contact the early intervention program in addition to informing the parents. MD EHDI will address this issue in the quality improvement activities of this grant.

Social and Cultural Determinants of Health in Baltimore City and Anne Arundel, Baltimore, Cecil, Prince George’s Counties

As is seen from the analyses above, certain jurisdictions in Maryland have higher numbers of infants who are LTF/D: Baltimore City; and Anne Arundel, Baltimore, Cecil, and Prince George’s counties. It has already been noted above that Maryland counties with the highest child poverty rates in 2012 includes Baltimore City (33.4%; up from 27% in 2003). In 2012, Cecil County had a child poverty rate of 16.2%, Prince George’s County was 15%, Baltimore County was 13%; and Anne Arundel County was 9.2%. By race/ethnicity, the highest percentage of children in poverty in the state is among black or African American children, with 23% living in poverty in 2012, followed by 17% of Hispanic or Latino children. Table 8 shows the race/ethnicity of the child population in each of the selected counties. MD EHDI does not receive race/ethnicity data on all infants who are LTF/D, but the incomplete data as well as anecdotal evidence based on the experience of follow-up coordinators suggest that a significant number of Maryland’s LTF/D population are Hispanic or Latino.

Table 8. Race/ethnicity of child population in selected counties in 2012 (Source: Kids Count Data)

Race/Ethnicity	Baltimore City	Anne Arundel County	Baltimore County	Cecil County	Prince George’s County
White	18.2%	64.1%	51.7%	80.5%	14.3%
Black or African American	70.2%	15.7%	30.4%	8.1%	55.8%
American Indian or Native Alaskan	0.2%	0.2%	0.2%	0.1%	0.2%
Asian	1.3%	3.0%	5.2%	1.1%	2.6%
Native Hawaiian or Pacific Islander	0.0%	0.0%	0.1%	0.1%	0.0%
Some Other Race	1.4%	2.4%	1.8%	1.5%	6.9%
Two or more races	3.7%	6.5%	4.7%	3.6%	3.7%

Hispanic or Latino	5.0%	8.1%	5.9%	5.0%	16.5%
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Baltimore City (70.2%) and Prince George’s (55.8%) counties have the highest percentages of Black or African-American children. Prince George’s (16.5%) and Anne Arundel (8.1%) have the highest percentages of Hispanic or Latino children. Baltimore City and Prince George’s counties also have high rates of child poverty. Hispanic or Latino and Black or African American children in these jurisdictions are more likely to be negatively impacted by poverty than elsewhere in the state. Children living in poverty have higher rates of unmet health needs; according to the 2009/10 National Survey of Children with Special Health Care Needs (09/10 NS-CSHCN), children with special health care needs (CSHCN) whose family income is 99% of the federal poverty line (FPL) or below are far more likely to have unmet health needs than wealthier families. Survey data also show that nationally, the rate of unmet need for hearing aids or hearing care is much greater among CSHCN living at 99% or below FPL (13.7%) than among CHSCN living at 400% or above FPL (2.4%).¹¹

As of 2011, among the Hispanic population in Maryland, the percentage who have obtained at least a bachelor’s degree was less than half that of the overall population in the state. Additionally, the percentage of Hispanics with less than a high school diploma was three times higher than that of the overall population. The median household income for Hispanics in Maryland was [REDACTED] lower than the statewide median income of [REDACTED]. The median household income for Blacks or African Americans in Maryland was [REDACTED] lower than the statewide median income of [REDACTED]. In 2010, over 25% of Hispanics in Maryland could not afford to see a doctor, and 38.5% of Hispanics did not have health insurance. Both percentages were significantly higher than those of Non-Hispanic Whites: Hispanics were more than 3 times more likely to not be able to afford to see a doctor, and they were more than 5 times more likely to be without insurance. Hispanics in Maryland had the highest percentage of people who reported having never visited a doctor for a routine checkup, 3.1%. This figure was 5.2 times higher than that of Non-Hispanic Whites, 4.4 times higher than Non-Hispanic Blacks and 1.2 times higher than Non-Hispanic Asians in Maryland.¹² During 2006-2010, 15% of Non-Hispanic Blacks or African Americans in Maryland reported that they could not afford to see a doctor at some time in the prior year, and 15.0% of Non-Hispanic Blacks or African Americans reported not having health insurance within the past year. Both percentages were significantly higher than those of Non-Hispanic Whites: Non-Hispanic Blacks or African Americans were nearly two times more likely to not be able to afford to see a doctor, and over two times more likely to be without health insurance than Non-Hispanic Whites.¹³

In 2011, 5% of children in Maryland under the age of 19 did not have health insurance. The percent of uninsured children under age 19 varied by jurisdiction: Anne Arundel County (3.7%) had the lowest percentage; Prince George’s County (6.4%) had the highest percentage, while

¹¹ The Data Resource Center for Child and Adolescent Health; accessed on 03/07/14 from www.childhealthdata.org

¹² Office of Minority Health and Health Disparities, Maryland Department of Health and Mental Hygiene. *Hispanics in Maryland: Health Data and Resources*. May 2013.

¹³ Office of Minority Health and Health Disparities, Maryland Department of Health and Mental Hygiene. *Blacks or African Americans in Maryland: Health Data and Resources*. December 2013.

Cecil County had 4.9%; Baltimore City had 4.6%, and Baltimore County had 5.1% of children under age 19 who did not have health insurance.¹⁴

Medically Underserved Areas/Populations (MUA/Ps) are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty and/or high elderly population. Currently, Anne Arundel County contains three MUA/Ps, which include a total of 12 census tracts. Baltimore City has twelve MUA/Ps including a total of 152 census tracts; Baltimore County has three MUA/Ps with a total of 10 census tracts. Prince George's County has eight MUA/Ps with a total of 49 census tracts.

METHODOLOGY

MD EHDI's Approach to Quality Improvement

From a quality improvement (QI) perspective, OGPSHCN is well-situated to address the needs identified in this assessment. NICHQ asserts that there are four essential elements for a quality improvement culture. The first element is 'leadership support.' Maryland's EHDI program has participated in a quality improvement effort in its past HRSA grant cycle, and the EHDI program director, Tanya Green, led that effort. The QI project also included team members from EHDI's advisory council and parents of young children with hearing loss. As a result, Maryland's EHDI program, including its leadership, has adopted a quality improvement culture.

The second element is 'continual feedback.' The key to this element is an environment where using data and feedback to keep measuring efforts are the norm. MD EHDI uses the Oz eSPT™ database, which allows for real-time tracking, reporting and analysis on critical issues such as LTF/D. MD EHDI's Program Audiologist is well versed in using the database for these purposes.

The third element is 'involvement of the customer in the solution.' Again, MD EHDI has learned the value of this approach during its previous NICHQ QI project, as team members included families served through the EHDI program as well as providers and their office staff.

The fourth element is 'willingness to fail to ultimately succeed.' MD EHDI has learned that this is often how the keys to success are identified, and how partners ultimately buy in to the QI process and outcomes.

Goals

The overall goal of this project is to reduce the percentage of infants who are LTF/LTD following a missed or failed newborn hearing screening from 31.34% to less than 20%. MD EHDI has identified 7 project goals using QI methodology to support this overall aim statement.

¹⁴ Advocates for Children and Youth KIDS COUNT Data Center. Accessed on 3/7/14 from <http://datacenter.kidscount.org/data/tables/4649-uninsured-children?loc=22&loct=5#detailed/5/3301-3303,3307,3316/true/867,133,38,35,18/any/10788,10789>

Project plans are fully outlined in the Work Plan section of this application and in Table 10 on pages 21.

In Year 1, Goal 1 is to form a team of committed stakeholders to assist in the QI efforts of this project.

The stakeholder team will be instrumental in overseeing the quality improvement work throughout this project. Fortunately, MD EHDI created a team for participation in the NICHQ project, and some members of this team will remain engaged. This FOA allows for hiring a staff member that can implement expansion of that team and organize its activities. Once the team is assembled, it will be necessary to educate team members to be fully conversant in the QI and EHDI processes. This objective will be coordinated with current OGPSHCN QI projects addressing medical homes for children with Developmental Disabilities and those with Epilepsy/Seizure Disorders. These projects receive technical assistance from the National Improvement Partnership Network (NIPN), and will provide valuable input on the QI process in primary care practice. Once the team has been provided with a foundation for its work, it will set about developing strategies, activities and measurement processes for chosen goals utilizing NICHQ and NIPN methodology. The team will then continue to review the work of MD EHDI by reviewing data on progress towards reducing LTF/D and recommending adjustments along the way.

Our Needs Assessment clearly pointed to specific geographic regions where we can focus our efforts to make the biggest impact in reducing our LTF/D numbers. In keeping with the QI directives taught in the NICHQ learning collaborative, MD EHDI will begin the work of this project in a limited area with small tests of change accomplished thru PDSA cycles. At the present time, it has not been determined which area will be targeted as we may be able to collaborate these efforts with a Medical Home Developmental Screening initiative that is occurring in Maryland and we do not yet know which area will work the best for this combined effort. Once that decision is made and the planned strategies implemented in that area, we will continue PDSA cycles to expand and spread in other geographic areas of the state throughout the Project period. As suggested in the FOA, we will make creating a team of stakeholders the first priority of our work and let that group’s ideas and suggestions drive subsequent activity. We expect to keep some of our NICHQ Learning Collaborative team members on this new team (see table ? below) and are therefore able to describe some of the goals and activities we expect to undertake based on previous input from those members.

Table 9. Stakeholders Team

Name of Partner/Organization	Stakeholder Category	Planned Role
Tanya D. Green	EHDI Coordinator	Team Lead
Erin Filippone	Program Audiologist	Data Person
TBD	Pediatric Audiologist	Collaborate to improve methods that will lead to LTF/D
TBD	Early Intervention Representative from Balto. City (major target area)	Collaborate to improve methods that will lead to LTF/D

TBD	Outreach Coordinator	Face to Face Outreach with providers in the target areas
TBD	Parent of a child with hearing loss (will seek parents residing in the target areas; will seek an English-speaking and a Spanish-speaking parent)	Collaborate to improve methods that will lead to LTF/D
Theresa Thompson	Program Follow up Coordinator	Follow up via phone, fax, and email
Leah Washington	Program Follow up Coordinator	Follow up via phone, fax, and email
TBD	Home Visiting	Collaborate to improve methods that will lead to LTF/D
TBD	WIC	Collaborate to improve methods that will lead to LTF/D

Goal 2 in Year 1 is to reduce LTF/D in Prince George’s county or Baltimore City through placement of a care coordinator in that jurisdiction to work with the Medical Home practices in the targeted areas.

Current MD EHDI data indicates that the highest LTF/D areas in Maryland are Prince George’s county and Baltimore City, and they are comparable. The decision of which jurisdiction to target will be based on logistical factors that are being evaluated as of this writing. Recent NICHQ learning collaborative work and OGPSHCN experience with developmental screening have revealed that primary care providers require not only education, but support in the field in order to implement best practices. A health educator serving as an outreach coordinator will be able to provide this support. The educator will be hired at the beginning of the project to be trained in QI principles and strategies, and to lay the groundwork for the core of the project. The coordinator will collect and adapt available tools for educating primary care practices and for data collection. This person will recruit practices in the chosen targeted jurisdiction, and collect baseline data from them. The coordinator will then work with each practice to identify strategies that can reduce LTF/LTD and improve successful completion of the EHDI 1-3-6 process, including communication back to public health for surveillance purposes. Lessons learned in these early adopter practices will be used to streamline and improve strategies as this work is spread to other jurisdictions in years 2 and 3.

In Year 2, Goal 1 is to implement strategies developed by the stakeholder team. As noted above, the stakeholder team will receive training to prepare members to develop strategies to improve LTF/LTD rate for infant hearing screening and follow up in primary care practices. The team will prioritize these strategies such that the outreach coordinator can begin implementing a strategy to use with participating practices once baseline data has been collected. Continual feedback will be solicited and outcomes measured in order to provide information to the stakeholder team at regular intervals. Strategies will be modified as necessary using Plan Do Study Act cycles and this process will be repeated as the coordinator moves down the prioritized list developed by the stakeholder team. The resulting honed strategies can then be spread to other jurisdictions in the last year of the project.

Goal 2 in Year 2 is to collaborate with other agencies serving the target population.

Another lesson learned through the NICHQ project and other OGPSHCN activities is that while primary care providers are responsible for following up on screening, they cannot accomplish this in a vacuum. Parents must be informed partners, and other child and family serving agencies can provide vital support. Maryland's Home Visiting Program and WIC Programs both reside in the Maternal and Child Health Bureau along with OGPSHCN. MD EHDI will work with these programs to develop strategies by which infants who are LTF/D may be reached through their home visitor or their local WIC center. Data will be collected at baseline and after implementation of these strategies to determine successful completion of the 1-3-6 protocol. These efforts will initially be targeted to the first jurisdiction and then successful strategies will again be spread to other jurisdictions. In return, MD EHDI can offer education to families about hearing screening and language development. WIC requires mothers to attend seminars periodically, and MD EHDI could fill one of these slots on a regular basis. Supplemental materials regarding language development could be provided to home visitors if desired and/or professional development could be offered.

In Year 3 Goal 1 will be to promote screening in the medical home and in birth centers/midwifery practices.

By Year 3 MD EHDI and OGPSHCN will have established relationships with many practices through various medical home QI initiatives. The program will target these practices, but also reach out through the MDAAP to other providers, to promote office infant hearing screening. Federally Qualified Health Centers and large multi-site practices are ideal in that they could identify a single site to provide screening for infants who need it. As home and birth center births continue to rise in Maryland, midwives are another target for infant hearing screening. This community based screening helps alleviate transportation issues and consolidate medical visits for families. MD EHDI will work with interested sites to identify sources of funding for screening equipment.

Goal 2 in Year 3 is to develop strategies to sustain processes shown to reduce LTF/D.

Once successful strategies are identified and implementation begun, sustainability will be a major goal of the project. Possibilities are already being considered by MD EHDI. Current CDC funding is enabling the development of data collection and dissemination of reminders for needed follow up that may allow one of the infant follow-up coordinators to fulfill care coordinator duties. OGPSHCN's long term plan for developing health care infrastructure for CSHCN includes the establishment of regional hubs that offer information and education to families, as well as care coordination support to providers. The tools that this project develops would allow the staff at such a hub to assist with sustaining strategies aimed at reducing LTF/D. One of the targets for outreach during this project is the audiology community, as reporting results of repeat screens and diagnostic evaluations is not consistent. Legislation is being proposed that will mandate reporting by these professionals, and this will help sustain gains made by the initial outreach of this project.

Goal 3 in Year 3 is to disseminate project findings to large scale audiences.

LTF/D is a widespread concern for EHDI programs. Once this project is completed, MD EHDI will apply to present the outcomes at the 2018 National EHDI conference and the 2018 annual AMCHP conference. Publication in a peer reviewed journal article will also be considered at project completion.

Objective 3.1: Present overall findings of project at the 2018 National EHDI conference

Objective 3.2: Present overall findings of project at the 2018 AMCHP Conference

Objective 3.3: Publish project findings in a peer reviewed journal article

WORK PLAN

Please see Attachment 1, p. 21 for a detailed chart of the Work Plan. Throughout the project period there will be two full time follow-up coordinators assigned to contact families and PCPs according to the protocol described above and in support of project activities under Goal 1. By this means, the foundation of the program will continue as improvements are implemented as a result of both the data system upgrades of the CDC grant and the activities of this project. Work on this project will begin by assembling a team of stakeholders to oversee the activities of this project and developing a contract for participation. The team will be educated in EHDI goals and processes, as well as in quality improvement strategies. The conceptual model of improvement cycles using Plan, Do, Study, Act will be demonstrated. Once prepared, the team will be tasked with developing an aim statement and outcome measures as well as prioritizing strategies for reaching this aim. As the team is being assembled and developing its work plan, the outreach coordinator will be hired. This coordinator will also be trained in EHDI principles and processes, as well as in receive detailed training in quality improvement and PDSA cycles. This will be augmented by the simultaneous NIPN coaching that OGPSHCN is receiving through ASD/DD and E/SD projects. The coordinator will also assemble and adapt tools to be used with primary care providers and community agencies to reduce LTF/D. Primary care practices in targeted jurisdictions will be recruited and the coordinator will collaborate with these practices to evaluate baseline individual LTF/D rates and pave the way for implementation of QI efforts in the second year.

Year 2 work will begin by collaboration with the Maryland Home Visiting program and with WIC. These two programs have ongoing contact with many of the families that are LTF/D and mutually beneficial relationships will be established. MD EHDI will offer professional development and resources to the Home Visiting program that can help reduce LTF/D rates. The content of these efforts will be advised by the stakeholder team and developed by MD EHDI staff and the outreach coordinator. Similarly, WIC requires mothers to attend educational sessions, and the plan is to develop a session based on EHDI principles and processes. Year 2 will also begin the detailed implementation of strategies prioritized by the stakeholder team. The outreach coordinator, under the guidance of MD EHDI staff, will begin implementing the highest priority strategy to reduce LTF/D using PDSA cycles in the targeted jurisdiction to evaluate impact. This strategy will be revised as needed, and the cycles will be repeated with subsequent strategies.

In Year 3, these QI cycles will continue, but the focus will be on spread and sustainability. The outreach coordinator will have honed strategies to bring to other jurisdictions that will be prioritized by LTF/D numbers. Making and keeping appointments for follow up hearing screening is a barrier to many families due to limited time and/or transportation resources. MD EHDI will utilize relationships established with primary care providers and midwives through previous work, years 1 and 2 of this project, and broader OGPSHCN activities. Interested providers will be supported in identifying funding sources for screening equipment. MD EHDI will provide training and be available for technical assistance. In addition, year 3 will evaluate potential funding for sustaining follow up coordinators and the outreach coordinator. It is possible that the electronic database modifications being implemented through CDC funding will

allow a follow up coordinator to take on some outreach duties. In addition, OGPSHCN is developing a regional hub model for supporting the care of CSHCN. This initiative will hopefully be piloted in the next few years through the use of Title V funds, and resources in the hub could be utilized to sustain successful strategies for reducing LTF/D. Finally, the impact of this work will be spread by MD EHDI staff applying to present findings from this project at the 2018 EHDI national conference and the 2018 AMCHP annual conference. A peer-reviewed journal publication will be considered as well.

Attachment 1: Work Plan

Table 10. Work Plan Year 1 (9/2014-8/2015)

Project Objective: By the end of Project Year 3 (August 31, 2017), MD EHDI will reduce the percentage of infants who are LTF/LTD following a missed or failed newborn hearing screening from 31.34% to less than 20%.

Goal 1: Form a team of committed stakeholders to assist in the QI efforts of this project		
Outcome Measure(s):		
<ul style="list-style-type: none"> ▪ Number of team members recruited ▪ Number of team members attending team meetings ▪ Retention of team members 		
Objective 1.1: Recruit team members		
Activities	Responsible Staff	Timeframe
Develop "Intent to Participate" contract for individuals that specifies member responsibilities and term of project	Tanya Green	By 10/31/2014
Contact qualified individuals to ascertain interest	Tanya Green	By 11/30/2014
Hold initial meeting with group of interested individuals; distribute contracts	Tanya Green	By 12/31/2014
Obtain signed contract from team members	Tanya Green	By 12/31/2014
Objective 1.2: Educate team members to be fully conversant in the QI and EHDI processes		
Activities	Responsible Staff	Timeframe
Coordinate with current OGPSHCN projects to access QI strategies learned from NIPN technical assistance	Tanya Green	January 2015
Review QI strategies learned from NICHQ learning collaborative and NIPN (National Improvement Partnership Network) with stakeholder team	Tanya Green	February 2015
Objective 1.3: Develop strategies, activities and measurement processes for chosen goals utilizing NICHQ and NIPN methodology		
Activities	Responsible Staff	Timeframe
Create an aim statement	Stakeholder team	March 2015
Develop goals for the project period	Stakeholder team	On-going
Develop activities to meet project goals	Stakeholder team	On-going

Goal 2: Reduce LTF/D in Prince George’s county or Baltimore City through placement of a care coordinator in that jurisdiction to work with the Medical Home practices in the targeted areas		
Measure(s):		
<ul style="list-style-type: none"> ▪ % decrease in LTF/D infants in this jurisdiction at end of Year 1 compared to baseline 		
Objective 2.1: Develop Care Coordinator position within MD EHDI		
Activities	Responsible Staff	Timeframe
Develop job description for care coordinator position	Tanya Green	By 9/30/2014
Recruit, hire and train care coordinator	Tanya Green	By 11/30/2014
Solicit Medical Home practices in target area for partnership	Care Coordinator	By 12/31/2014
Collect baseline data of LTF/D infants served by these practices	Erin Filippone	By 12/31/2014
Objective 2.2: Staff Care Coordinator position within MD EHDI		
Activities	Responsible Staff	Timeframe
Place care coordinator in selected Medical Home practices in target area	Tanya Green	By 01/02/ 2015
Monitor data of identified infants’ progress thru 1-3-6 protocol	Erin Filippone	On-going
Amend and/or spread successful strategies to other target practices/areas through Years 2 and 3	Care Coordinator	On-going

Table 11. Work Plan Year 2 (9/2015-8/2016)

Project Objective: By the end of Project Year 3 (August 31, 2017), MD EHDI will reduce the percentage of infants who are LTF/LTD following a missed or failed newborn hearing screening from 31.34% to less than 20%.

Goal 1: Collaborate with other agencies serving the target population in Prince George’s county or Baltimore City		
Measure(s):		
<ul style="list-style-type: none"> ▪ % decrease in LTF/D infants in the Home Visiting program at end of Year 2 compared to baseline ▪ % decrease in LTF/D infants in the WIC program at end of Year 2 compared to baseline ▪ % decrease in total LTF/D infants at end of Year 2 compared to baseline 		
Objective 1.2: Develop a working relationship with Home Visiting		
Activities	Responsible Staff	Timeframe
Determine strategies to identify and reach LTF population thru their already established contact with Home Visiting	Tanya Green	By 09/30/2015

Develop processes to be employed by Home Visiting staff in facilitating the infants' completion of the EHDI 1-3-6 process	Tanya Green	By 10/31/2015
Collect baseline data of LTF/D infants served by Home Visiting	Erin Filippone and Home Visiting staff	By 10/31/2015
Implement processes developed	Home Visiting staff	11/01-12/31/2015
Monitor data of identified infants' progress thru 1-3-6 protocol	Erin Filippone	On-going
Amend and/or spread successful strategies to other target regions through Year 3	Tanya Green	On-going
Objective 1.2: Develop a working relationship with WIC		
Activities	Responsible Staff	Timeframe
Determine strategies to identify and reach LTF population thru their already established contact with WIC	Tanya Green	By 01/31/2016
Develop processes to be employed by WIC staff in facilitating the infants' completion of the EHDI 1-3-6 process	Tanya Green	By 02/28/2016
Collect baseline data of LTF/D infants served by WIC	Erin Filippone and WIC staff	By 02/28/2016
Implement processes developed	WIC staff	03/01-04/30/2016
Monitor data of identified infants' progress thru 1-3-6 protocol	Erin Filippone	On-going
Amend and/or spread successful strategies to other target regions through Year 3	Tanya Green	On-going
Goal 2: Implement strategies developed by stakeholder team		
Outcome Measure(s):		
<ul style="list-style-type: none"> ▪ To be determined based on strategies chosen 		
Objective 2.1: Select and implement chosen specific strategy #1		
Activities	Responsible Staff	Timeframe
Collect baseline data	Erin Filippone	By 10/01/2015
Implement strategy	Assigned stakeholder(s)	By 10/01/2015
Monitor related data	Erin Filippone	On-going
Amend and/or spread strategy based on data collected	Assigned stakeholder(s)	On-going
Objective 2.2: Select and implement chosen specific strategy #2		
Activities	Responsible Staff	Timeframe
Collect baseline data	Erin Filippone	By 01/01/2016
Implement strategy	Assigned stakeholder(s)	By 01/01/2016

Monitor related data	Erin Filippone	On-going
Amend and/or spread strategy based on data collected	Assigned stakeholder(s)	On-going
Objective 2.3: Select and implement chosen specific strategy #3		
Activities	Responsible Staff	Timeframe
Collect baseline data	Erin Filippone	By 04/01/2016
Implement strategy	Assigned stakeholder(s)	By 04/01/2016
Monitor related data	Erin Filippone	On-going
Amend and/or spread strategy based on data collected	Assigned stakeholder(s)	On-going

Table 12. Work Plan Year 3 (9/2016-8/2017)

Project Objective: By the end of Project Year 3 (August 31, 2017), MD EHDI will reduce the percentage of infants who are LTF/LTD following a missed or failed newborn hearing screening from 31.34% to less than 20%.

Goal 1: Promote screening in the medical home and in birth centers/midwifery practices		
Measure(s):		
<ul style="list-style-type: none"> ▪ % decrease in LTF/D of out of hospital births at end of Year 3 compared to baseline 		
Objective 1.2: Develop working relationships with medical homes		
Activities	Responsible Staff	Timeframe
Select receptive practices and collect baseline data on infants in these practices	Care Coordinator	On-going thru Year 3
Conduct site visits to inform and educate practices about congenital hearing loss and EHDI	Care Coordinator	On-going thru Year 3
Facilitate purchase of screening equipment	Tanya Green	On-going thru Year 3
Monitor data of progress thru 1-3-6 protocol for infants from selected practices	Erin Filippone	On-going thru Year 3
Amend and/or spread successful strategies to other practices	Care Coordinator	On-going thru Year 3
Objective 1.2: Develop working relationships with birth centers/midwifery practices		
Activities	Responsible Staff	Timeframe
Select receptive practices and collect baseline data on infants in these practices	Care Coordinator	On-going thru Year 3
Conduct site visits to inform and educate practices about congenital hearing loss and EHDI	Care Coordinator	On-going thru Year 3
Facilitate purchase of screening equipment	Tanya Green	On-going thru Year 3

Monitor data of progress thru 1-3-6 protocol for infants from selected practices	Erin Filippone	On-going thru Year 3
Amend and/or spread successful strategies to other practices	Care Coordinator	On-going thru Year 3
Goal 2: Develop strategies to sustain processes shown to reduce LTF/D		
Outcome Measure(s):		
<ul style="list-style-type: none"> ▪ # of alternative funding sources identified ▪ # of new practices connected thru HIE ▪ Department acceptance of regulatory reform proposal 		
Objective 2.1: Investigate alternative funding for follow-up coordinator and care coordinator positions		
Activities	Responsible Staff	Timeframe
Open discussions with Maternal and Child Health Bureau Director regarding Title V funds	OGPSHCN office director	By 10/31/2016
Investigate combining MD EHDI Care Coordinator activities with OGPSHCN's regional hub care coordinators	OGPSHCN medical director	By 01/01/2017
Develop new job description for combined MD EHDI Care Coordinator/Regional Hub Coordinator	OGPSHCN medical director	By 04/01/2017
Objective 2.2: Promote connection of hospitals, birth centers, medical homes and audiology practices to the Program thru the state's HIE		
Activities	Responsible Staff	Timeframe
Educate end users regarding the benefits of connection thru the HIE	Erin Filippone	On-going thru Year 3
Facilitate contact between individual site IT specialists and state HIE	Erin Filippone	On-going thru Year 3
Objective 2.3: Propose regulatory reform to require that all outpatient hearing screening and diagnostic test results are reported to the state EHDI program		
Activities	Responsible Staff	Timeframe
Draft new regulations	Tanya Green	By 10/31/2016
Submit draft to Department for review	OGPSHCN office director	By 12/01/2016
Goal 3: Disseminate project findings to large scale audiences		
Measure(s):		
<ul style="list-style-type: none"> ▪ # of presentations of project findings 		

▪ Publication of article		
Objective 3.1: Present overall findings of project at the 2018 National EHDI conference and 2018 AMCHP Conference		
Activities	Responsible Staff	Timeframe
Design and construct poster session	Care Coordinator	By 04/01/2017
Present poster session at conference	Care Coordinator	Conference dates
Objective 3.2: Publish project findings in a peer reviewed journal article		
Activities	Responsible Staff	Timeframe
Draft article for a peer-reviewed journal	OGPSHCN medical director	By 04/01/2017
Submit article for publication in a peer-reviewed journal	OGPSHCN medical director	By 07/01/2017

RESOLUTION OF CHALLENGES:

The proposed grant activities will require assembly of the appropriate key stakeholders to review and inform the project. Fortunately, Maryland's participation in the NICHQ learning collaborative allowed us to identify appropriate participants, and in some cases the individuals who might serve on the team. Collaboration with WIC and Home Visiting poses a challenge, as there is not a history of working jointly on projects. However, in the past year DHMH has reorganized such that OGPSHCN, WIC and Home Visiting all reside in the Maternal Child Health Bureau. Leadership meetings allow for information sharing and identification of methods by which EHDI can assist these entities in meeting their own goals. For example, WIC is required to hold periodic educational seminars for their clients. The EHDI program can help address this need on an ongoing basis.

Medical Homes and midwifery practices will benefit by increasing client satisfaction and implementing best practices for infant care. MD EHDI has made progress over the past year in developing collaboration with at least one of the state's birthing centers, laying the groundwork for continued expansion in the midwife community. The OGPSHCN experience in the QI learning collaboratives for children with ASD/DD and E/SD will provide resources such as infrastructure and technical assistance from an experienced center, NIPN, to connect with practices and assist them in implementing improvements.

Data collection from the Maryland's early intervention program has been a challenge in the past. However, a current project funded by the CDC has allowed data exchange between MD EHDI and the early intervention program. Therefore, data on referrals and entry into services for children identified with hearing loss will be available for evaluating the outcomes of this project.

EVALUATION AND TECHNICAL CAPACITY

The complete Evaluation Plan is included in Table 13, p. 29-31, and details the type and timing of the measures to be taken. Prior to the time that this HRSA grant would be awarded, many baseline LTF/LTD measures will have already been taken in accordance with current HRSA and CDC funded projects. These measures will also be applicable for comparison in assessing the impact of the proposed grant activities of this project on Maryland's LTF/LTD rates. The electronic database upgrades funded through the CDC will be implemented during the first year of the current proposed funding, however they will not be targeted to the specific areas proposed in this project, and therefore results will be independently measurable for this HRSA grant's project period. OGPSHCN's Health Policy Analyst will assist MD EHDI in data gathering and analysis activities for project evaluation.

Data for evaluation activities are obtainable through MD EHDI's database, OZ Systems eSP™. This system was originally funded in 2007 through a Maternal and Child Health Bureau (MCHB) block grant and system upgrades were completed through a CDC grant awarded in 2009. OZ Systems has over 14 years of experience in providing database tools for UNHS/EHDI programs at hospital, state, and national levels to organize and manage the data that allows for successful tracking and follow-up activities. The CEO of OZ Systems, Terese Finitzo, Ph.D., has an extensive research and clinical practice background in audiology and in building early detection infrastructures to support EHDI programs. The company's lead liaison to the

Maryland program is Brenee Mitchell, MS, who provides guidance and on-going support to the program.

OGPSHCN is currently collaborating with Parents' Place of Maryland (PPMD) on two HRSA MCHB projects focused on improving the quality of care for CSHCN. One project targets children with Autism Spectrum Disorders and other Developmental Disabilities (ASD/DD) and the other targets children with Epilepsy/Seizure Disorders (E/SD). A major activity in both grants is the development and implementation of QI learning collaboratives with primary care practices, and coaching is available from the National Improvement Partnership Network (NIPN). This coaching will strengthen OGPSHCN's QI abilities as well as partnership with the Maryland Pediatric Improvement Partnership (MPIP), and will inform the QI activities of this grant.

Table 13 - Evaluation Plan

Overall Goal: Reduce the number of Maryland infants who are lost to follow-up or lost to documentation (LTF/LTD) from 31.34% (2012 baseline measure) to no more than 20% .			
Overall Measure:	Outcome Measures	Data Sources/Timing	Expected Outcome(s)
By the end of Project Year 3 (August 31, 2017), MD EHDl will reduce the percentage of infants who are LTF/LTD following a missed or failed newborn hearing screening from 31.34% to less than 20%.	% of infants LTF/D following a failed or missed inpatient hearing screen	MD EHDl OZ eSP™ database/August 31, 2015/16/17	Overall Measure will show steady 5% reduction in LTF/LTD each year and will ultimately result in a Program LTF/D rate of less than 20% by the end of the Project period

Year 1

Goal 1: Form a team of committed stakeholders to assist in the QI efforts of this project			
Measures:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
Number of team members recruited	# of Signed “Intent to Participate” contracts	Once / Team members	MD EHDl will recruit at least 5 team members
Number of team members in attendance at team meetings	# of member signatures on Meeting sign in sheet	Quarterly / Meeting sign in sheet.	Each team member will miss no more than 1 meeting per quarter.
Retention of team members throughout the Project period.	# of member signatures on Meeting sign in sheet	Quarterly / Meeting sign in sheet.	No more than 1 member will drop off of the team each year of the project period.
Goal 2: Reduce LTF/D in Prince George’s county or Baltimore City through placement of a care coordinator in that jurisdiction to work with the Medical Home practices in the targeted areas			
Measure:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
% decrease in LTF/D infants in the selected jurisdiction at end of Year 1	# of infants LTF/D in selected jurisdiction	Quarterly / Program database (Initial baseline data will be taken prior to start of Project.)	By the end of Project Year 1, the number of infants LTF/D in the selected jurisdiction will decrease by at least 5% (Further annual reductions of at least 5% are expected as activity continues thru Years 2 and 3)

Year 2

Goal 1: Collaborate with other agencies serving the target population in Prince George’s county or Baltimore City			
Measures:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
% decrease in LTF/D infants in the Home Visiting program at end of Year 2 compared to baseline	# of infants LTF/D within the Home Visiting population	Quarterly;Program database (Initial baseline data will be taken prior to start of Project.)	By the end of Project Year 2, the number of infants LTF/D in the Home Visiting population will decrease by at least 5% (A further annual reduction of at least 5% is expected as activity continues thru Year 3)
% decrease in LTF/D infants in the WIC program at end of Year 2 compared to baseline	# of infants LTF/D within the WIC population	Quarterly;Program database (Initial baseline data will be taken prior to start of Project.)	By the end of Project Year 2, the number of infants LTF/D in the WIC population will decrease by at least 5% (A further annual reductions of at least 5% is expected as activity continues thru Year 3)
% decrease in total state LTF/D infants at end of Year 2 compared to baseline 2012 state data	Total # of infants LTF/D in Maryland	Quarterly;Program database	By the end of Project Year 2, the total number of infants LTF/D in Maryland will be no more than 20% (A further annual reduction is expected as grant activities continue thru Year 3 and beyond)
Goal 2: Implement strategies developed by stakeholder team			
Measure:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
To be determined based on strategies chosen	To be determined based on strategies chosen	To be determined based on strategies chosen	Strategies chosen by stakeholder group will contribute to the overall reduction in the total number of infants LTF/D in Maryland

Year 3

Goal 1: Promote screening in the medical home and in birth centers/midwifery practices			
Measures:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
% decrease in LTF/D of out of hospital births at end of Year 3 compared to baseline	# of infants LTF/D within the Out of Hospital birth population	Quarterly; Program database (Initial baseline data will be taken prior to start of Project.)	By the end of Project Year 3, the number of infants LTF/D in the Out of Hospital birth population will decrease by at least 5%
Goal 2: Develop strategies to sustain processes shown to reduce LTF/D			
Measure:	Outcome Measures	Timing/ Data Sources	Expected Outcome(s)
Identification of alternative funding sources for follow-up coordinator and care coordinator positions	# of alternative funding sources identified	On-going thru year 3 / To be determined	MD EHDI will find or create funding for continuation of the Program follow-up coordinator and care coordinator positions
% increase of new practices connected to MD EHDI thru the state HIE	# of new practices connected to MD EHDI thru the state HIE	On-going thru year 3 / MD EHDI OZ eSP™ database	By the end of Project Year 3, 10 new practices will be connected to MD EHDI thru the state HIE
Department acceptance of regulatory reform proposal	Enactment of regulatory reform requiring outpt screening and diagnostic testing of infants to be reported to MD EHDI	By August 31, 2017 / Code of Maryland Regulations (COMAR)	By the end of Project Year 3, new regulation will be enacted in Maryland that requires any professional performing outpatient screening and/or diagnostic testing of infants to report those test results to MD EHDI
Goal 3: Disseminate project findings to large scale audiences			
Presentations of project findings	# of presentations of project findings	By December 31, 2018 / National EHDI and AMCHP Conferences	Following the conclusion of the Project period, OGPSHCN will present Project findings at State and National conferences
Publication of Project outcomes in a peer-reviewed journal	Acceptance of article by a peer-reviewed journal	By December 31, 2018/ To be determined	Following the conclusion of the Project period, OGPSHCN will publish an article in a peer-reviewed journal that describes the Project outcomes

ORGANIZATIONAL INFORMATION

The Maryland Infant Hearing Program

MD EHDI is part of OGPSHCN within MD DHMH. The program has historically been funded through the Title V MCHB block grant and supplemental grants from HRSA and CDC. MD EHDI is well-qualified to direct and conduct the activities outlined in this grant proposal. MD EHDI is currently staffed with four full-time employees: a program chief, a program audiologist and two follow-up coordinators. Tanya D. Green, M.S., CCC-A is the program chief of MD EHDI. Her career path includes public health, hospital, university, public school, and private practice experience, has always included an emphasis in the hearing, communicative, and educational needs of children. Erin Filippone, M.Ed., CCC-A is the Program Audiologist. She has extensive previous experience as a pediatric audiologist in a pediatric ENT practice. Theresa Thompson, BA, MFA serves as a follow-up coordinator and brings experience in teaching and public health administration. Leah Washington also serves as a follow-up coordinator and possesses a Master of Arts degree in Criminal Justice and Counseling with a concentration in Law Enforcement and HIV Counseling and Testing. Leah has experience as a public health educator and HIV prevention case manager.

MD EHDI directs and staffs Maryland's Universal Newborn Hearing Screening Advisory Council, which was created by the UNHS legislation enacted in 2000. The council members, who are drawn from a broad stakeholder community, provide consultation and guidance to the program in its operation and delivery of services.

MD EHDI has a long-standing relationship with The Hearing and Speech Agency (HASA) in Baltimore. This agency is dedicated to improving the lives of children and adults by meeting their communication needs. HASA is a service provider, information center, and advocate for people with deafness, hearing loss, speech/language disabilities, and other communication differences. HASA has provided quality care for individuals, their families, and the community since 1926. MD EHDI has benefited from this agency's willingness to host and co-fund a variety of MD EHDI activities and meetings including the Universal Newborn Hearing Screening Advisory Council meetings and the annual MD EHDI Stakeholders Meeting.

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

The OGPSHCN is Maryland's Title V organization serving CYSHCN. It is one of four offices within the Maternal Child Health Bureau in the Prevention and Health Promotion Administration of the Maryland Department of Health and Mental Hygiene. The mission of the OGPSHCN is to assure a comprehensive, coordinated, culturally effective, and consumer-friendly system of care that meets the needs of Maryland's CYSHCN and their families. The OGPSHCN strives to provide CYSHCN in Maryland with access to services and medical care that meet with the six core outcomes identified by the federal MCHB (family-professional partnerships; medical home; adequate health insurance and financing; early and continuous screening; easy-to-use community-based services; and youth transition to adulthood). The OGPSHCN has 23 employees and an operating budget of approximately [REDACTED], 80% of which comes from federal funds through the Title V Block grant. OGPSHCN encompasses several different

programs that serve children and families throughout the state, including the Universal Newborn Hearing Screening Program; Infrastructure and Systems Development; Children's Medical Services; Newborn Metabolic Screening Follow-Up Program; Newborn Critical Congenital Heart Disease Screening Follow-Up, Sickle Cell Disease Follow-Up Program; and Birth Defects Reporting and Information System.

The OGPSHCN is well-qualified to carry out the various implementation activities of the proposed Project. The OGPSHCN staff is comprised of varied professionals including clinicians and public health professionals who are experienced in data gathering and translation activities such as needs assessments, as well as communicating and disseminating information in a variety of formats and settings. Staff has extensive experience in program and policy development; data collection and evaluation; and grants and contract management. The office Medical Director, Dr. Deborah Badawi, is a developmental pediatrician with 20 years of experience; 15 of those years were spent specifically serving CYSHCN. Meredith Pyle, Program Chief for Infrastructure and Systems Development OGPSHCN, has over 6 years' experience in data analysis, reporting, needs assessments, and program evaluation for federal and state grants including the Title V Maternal and Child Health Block Grant. The OGPSHCN has a long history of accomplishments that have positively impacted the health and well-being of CYSHCN and their families in Maryland. In recent years, the OGPSHCN has been a leader in the state in developing ongoing, meaningful partnerships with family organizations and developing a statewide network to link CYSHCN and families with services in their communities; and in working on policy and practice level change to support improvements in developmental screening. OGPSHCN has also been involved in leadership, management and collaboration on numerous grant activities and cooperative agreements. Recent examples include several years of HRSA funding directly to OGPSHCN for a *Statewide Early Hearing Detection and Intervention System*; collaboration on Maryland's *State Systems Development Initiative (SSDI)* grant; and participation in the collaborative agreement supporting the New York Mid-Atlantic Genetics Consortium. Ongoing collaboration and partnerships with numerous public and private agencies provide mechanisms that facilitate implementation of OGPSHCN services and activities. Examples of collaborative partners include: 24 local health departments; local hospitals; pediatric specialty centers including Johns Hopkins Hospital, University of Maryland Medical Center, Kennedy Krieger Institute, and Children's National Medical Center; The Maryland Chapter of the AAP; Medicaid and Medicaid managed care organizations; Mental Hygiene Administration; the Developmental Disabilities Administration; the Department of Disabilities; the Maryland State Department of Education and local school systems; numerous family advocacy organizations and disability/disease-specific service organizations.

OGPSHCN prides itself on the depth of its partnership with the state Family Voices and F2F organization, the Parents' Place of Maryland PPMD. The Maryland Consortium for CYSHCN (CoC) is co-led by OGPSHCN and PPMD, and the Title V Block Grant application is reviewed by PPMD annually.

Attachment 2: Staffing Plan and Job Descriptions of Key Personnel

Position: Program Chief of the Maryland Early Hearing Detection and Intervention Program (MD EHDI) (Tanya D. Green, M.S., CCC-A, .85 FTE in-kind) Ms. Green is the Program Chief of the Maryland Early Hearing Detection and Intervention Program (MD EHDI) with the Office for Genetics and People with Special Health Care Needs (OGPSHCN) in the Maryland Department of Health and Mental Hygiene (MD DHMH). Ms. Green brings over seventeen years of experience as an educational and clinical audiologist to her position with MD EHDI. Her career path, which includes hospital, university, public school, and private practice experience, has always included an emphasis in the hearing, communicative, and educational needs of children. Ms. Green's current responsibilities include overseeing MD EHDI, procuring program funding, and building strategic partnerships with MD EHDI stakeholders.

Project responsibilities:

- Provide leadership and coordination for the project in partnership with parent leaders and Program Audiologist; provide oversight of project activities
- Assist with the hiring of the Outreach Coordinator; work with outreach coordinator to develop and implement QI methods of reducing LTF/D
-
- Attend annual National EHDI Meeting and encourage parent attendance to the National EHDI Meeting
-
- Speak and/or provide poster session materials at the annual Maryland Academy of Audiology meetings and Maryland Chapter of American Academy of Pediatrics (MDAAP) events
- Site visits to providers to educate, promote reporting, and to solicit support for the MD EHDI program
- Plan and hold strategic planning meetings to devise a proposal for the future of the MD EHDI and MD EHDI; review the mission and vision of the program to address any changes or additions required; draft and finalize plan based on stakeholder feedback

Position: Program Audiologist for MD EHDI (Erin D. Filippone, M.Ed., CCC-A, .75 FTE in-kind.) Ms. Filippone is the Program Audiologist for MD EHDI. She has over four years' experience in this position and seventeen years prior experience as a clinical pediatric audiologist in Maryland. Ms. Filippone's current responsibilities include supervising the MD EHDI Follow-Up Coordinators, promoting follow-up diagnostic and risk management care for identified infants, serving as the hospital liaison for MD EHDI, database management including program statistics, and strategic planning for the program.

Project responsibilities:

- Assist with coordination for the project in partnership with parent leaders and MD EHDI Program Chief; assist with oversight of project activities
- Assist with all aspects of the parent involvement plan
- Attend annual National EHDI Meeting
- Assist in all aspects of developing new outpatient screening sites in identified jurisdictions
- Serve as the data person for the project
- Speak and/or provide poster session materials at the annual Maryland Academy of Audiology meetings and Maryland Chapter of American Academy of Pediatrics (MDAAP) events

- Site visits to providers to educate, promote reporting, and to solicit support for the MD EHDI program
- Assist with strategic planning meetings to devise a proposal for the future of the MD EHDI and MD EHDI; review the mission and vision of the program to address any changes or additions required; draft and finalize plan based on stakeholder feedback

Position: Follow-Up Coordinators for MD EHDI (Theresa Thompson, B.A., M.F.A. and Leah Washington, M.A., 2.0 FTE.) Ms. Thompson is a Follow-Up Coordinator for MD EHDI. She has held this position for seven years and brings experience in teaching and public health administration. Ms. Thompson's current responsibilities include contact with families and providers in follow-up to infants who fail or miss their hearing screen, serves as a resource for families and providers, and facilitating access to follow-up care. Ms. Washington,

Project responsibilities:

- By 2 weeks post-hospital discharge, make initial contact by letter to parents and by fax to primary care provider (PCP), if known, of infants with a failed or missed screen indicating that the infant requires a newborn hearing screen; document occurrence of contact in database
- If no hearing screen follow-up documentation has been received by 4 weeks post-hospital discharge, make second contact by phone to parents and by phone to PCP (if known) indicating that the infant still requires a newborn hearing screen; document occurrence of contact in database
- If no hearing screen follow-up documentation has been received by 6 weeks post-hospital discharge, make third and final contact by most appropriate means (including certified mail, phone call, and/or fax) to parents and PCP (if known) indicating that the infant still requires a newborn hearing screen; document occurrence of contact in database
- Assist in other project activities as needed

Position: Director, Office for Genetics and People with Special Health Care Needs

(OGPSHCN) (Donna X. Harris, .10 FTE in-kind.) Ms. Harris is the Director of OGPSHCN. Her current responsibilities include overseeing OGPSHCN programs including MD EHDI, budget and fiscal procurement activities, management of personnel and processes, and strategic planning for OGCSHN programs and activities.

Project responsibilities:

- Manage and oversee the fiscal components of the project
- Hire to fill outreach coordinator

Position: OGPSHCN Medical Director (Deborah G. Badawi, M.D., .15 FTE in-kind.) Dr. Badawi is the Medical Director for OGPSHCN. Her current responsibilities include program management and development for various initiatives, interfacing with state and local medical professionals and associations, legislative and clinical guidance, and grants management and support. Dr. Badawi brings nineteen years of experience in pediatric medicine with a concentration in developmental disabilities. Immediately prior to her work with OGPSHCN, she was the Medical Director of the Maryland School for the Blind for eight years. She has also been the dental liaison for MD AAP and currently serves on the MD AAP Behavioral and Developmental Pediatrics and CSHCN Committees.

Project responsibilities:

- Site visits to providers to educate, promote reporting, and to solicit support for the MD EHDI program
- Assist with strategic planning meetings to devise a proposal for the future of the MD EHDI and MD EHDI; review the mission and vision of the program to address any changes or additions required; draft and finalize plan based on stakeholder feedback
- Provide support for the development of sustainability plans.
- Assist in generalization of impact through facilitating AMCHP presentation and possible peer-reviewed article.

Position: OGPSHCN Health Policy Analyst and Title V CSHCN Specialist (Meredith J. Pyle, .20 FTE in-kind.) Ms. Pyle is the Health Policy Analyst and Title V CSHCN Specialist for OGPSHCN. She has over seven years' prior experience working with young CSHCN and their families and has worked with OGPSHCN for almost four years. She is pursuing a doctoral degree in public policy. Ms. Pyle's current responsibilities include a variety of analytic, administrative, and coordinative tasks in support of statewide public health policy development and strategic planning, as well as developing program implementation and program evaluation strategies that align with federal MCHB/Title V guidelines and state regulations and mandates.

Project responsibilities:

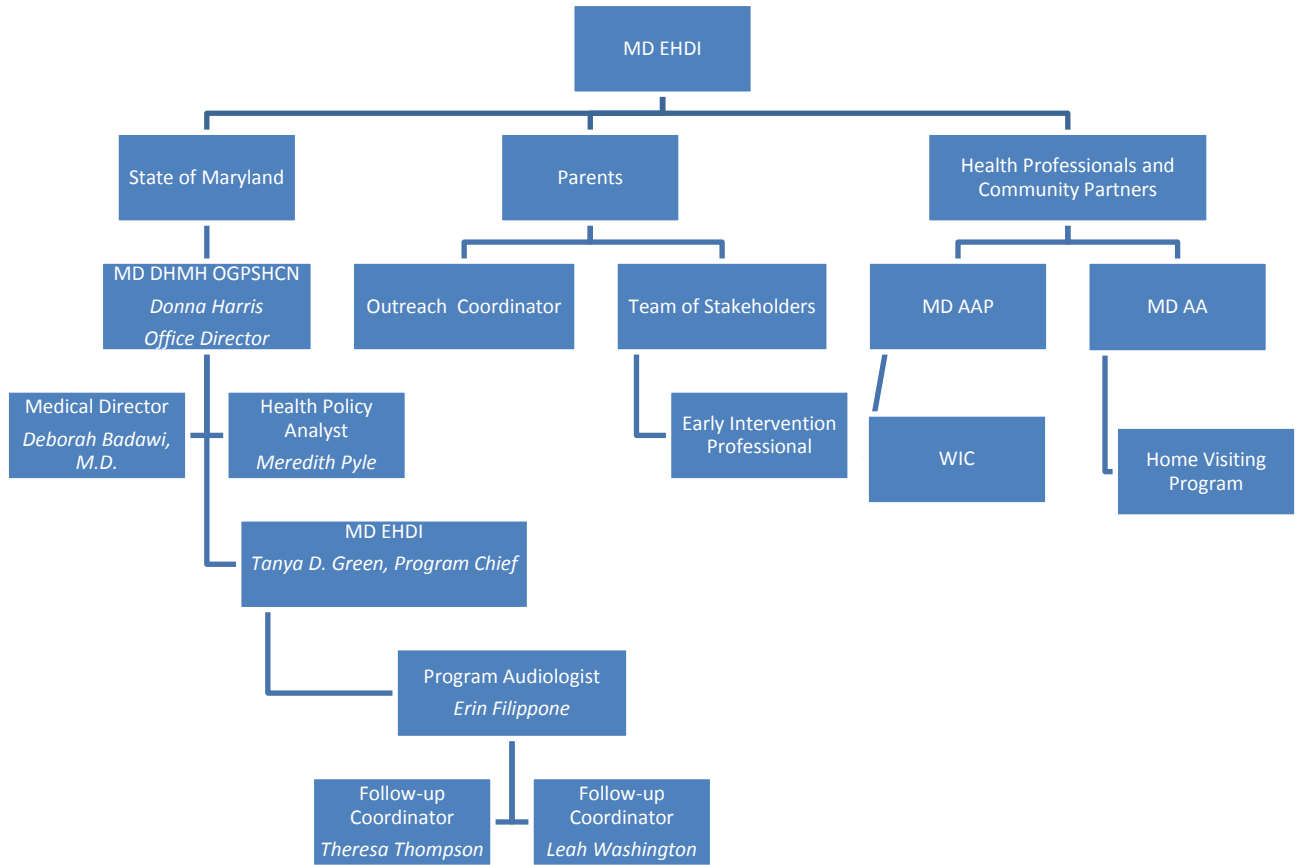
- Analyze MD EHDI program data to identify jurisdictions of greatest need for LTF/D activities.
-
- Conduct project evaluation activities

Position: Outreach Coordinator (1.0 FTE, TBA) This position will be filled by a Community Health Educator who will be responsible for day to activities of this project:

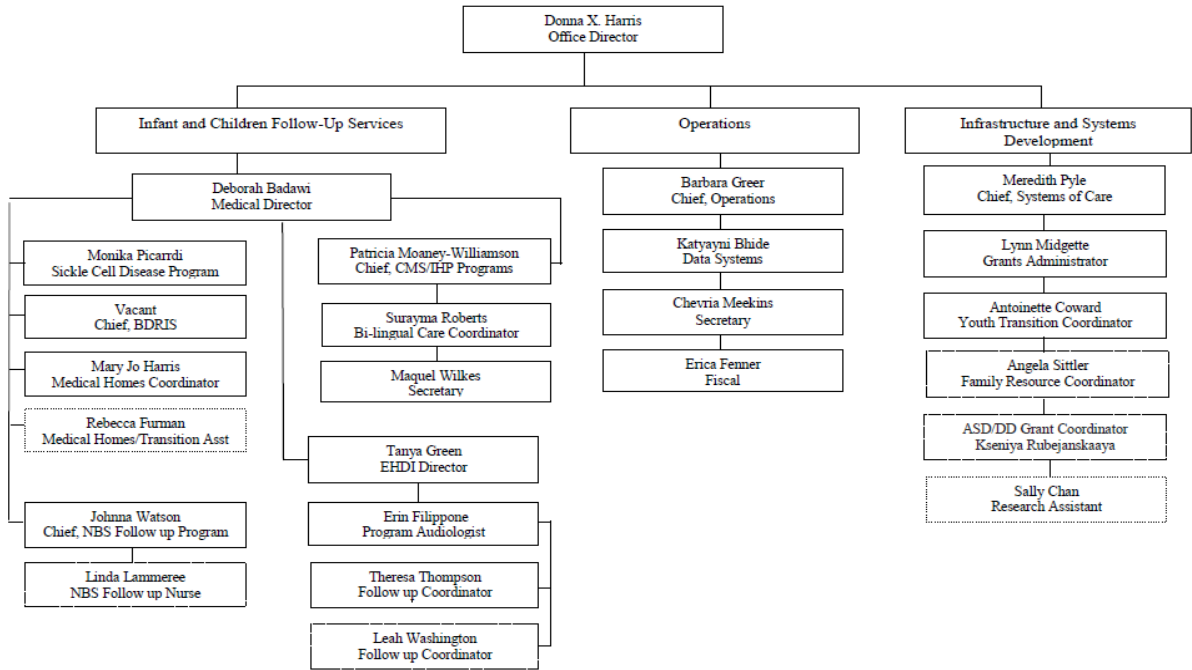
- Assemble and modify tools needed to train health care and community providers on EHDI principles and processes.
- Recruit providers to participate in QI activities in targeted jurisdiction.
- Assemble and modify materials to share with Home Visiting and WIC.
- Implement strategies identified by stakeholder team and conduct PDSA cycles to improve LTF/D rates in targeted jurisdictions.

Ongoing collection of outcome data to be shared with MD EHDI staff and stakeholder team

Attachment 5: Project Organizational Chart



Maryland Department of Health and Mental Hygiene
 Prevention and Health Promotion Administration
 Maternal and Child Health Bureau
 Office of Genetics and People with Special Health Care Needs



Attachment 7: Accomplishment Summary

Period Covered: September 1, 2013 - February 28, 2014

The program's ability to follow up on babies needing follow up hearing screening and diagnostic testing improved with the hiring of a second follow up coordinator. The new coordinator is extremely efficient and is a good fit for the program. Parent involvement in many aspects of the program has increased. HRSA award funds allowed two parents to attend the 2013 National EHDI Meeting in Arizona. Both parents expressed their gratitude for the opportunity to attend. One parent stated that she left the meeting feeling encouraged about the opportunities that lie ahead for her child. Additionally, one MD EHDI staff member was able to attend the National EHDI Meeting using HRSA award funds, and two staff attended using funding from another source. Parents have also actively participated in the NICHQ (National Initiative for Children's Quality) Learning Collaborative, providing valuable input to promote positive changes which can be spread from a small population, to populations statewide. Through a HRSA grant sub-award to a non-profit organization, "Parent Connections" was established. "Parent Connections" allows parents to serve as mentors, assisting families who have a child or children with hearing loss. Parents have assisted with the planning of the annual state EHDI stakeholders meeting and they actively participate on the state Hearing Advisory Council.

GOALS AND OBJECTIVES:

Overall Measure: Percent of Maryland infants who are lost to follow-up/lost to documentation following a missed or failed newborn hearing screening.

Goal 1: To increase the number of timely referrals to follow-up of infants who fail or miss their newborn hearing screening.

Measures:

- 1.1 The percent of MD EHDI follow-up cases that have documented initial contact by 2 weeks.
- 1.2 The percent of MD EHDI follow-up cases that have documented second contact by 4 weeks.
- 1.3 The percent of MD EHDI follow-up cases that have documented second contact by 6 weeks.

Objectives:

1. Increase the number of timely contacts with the parents and care providers (primary care doctor, audiologists, or other associated providers) of infants **who miss** their newborn hearing screening throughout the entire project.
2. Increase the number of timely contacts with the parents and care providers (primary care doctor, audiologists, or other associated providers) of infants **who fail** their newborn hearing screening throughout entire project.

Results:

Statistical data was obtained by querying the MD EHDI database to determine the number of babies for which the data system provided the appropriate reminder alert to indicate the need for follow up action. Follow up action is taken at 2, 4, and 6 weeks post discharge. An analysis of the data revealed system limitations of which the database vendor has been made aware and is working toward resolution. The percentages obtained in the data reflected cases in which a scheduled appointment was pending, and these are cases which would not receive follow up contact until after the scheduled appointment or if the family did not keep the scheduled appointment. It was also discovered that there were some instances in which the data system was not automatically disabling the alert that notifies the follow up coordinators that an infant has completed the screening phase. In some of these cases the alert was manually disabled, but the data is reflecting many cases that it should not be counting. Lastly, a non-data system related

issue is that follow up coordinators were sending follow up letters but not documenting the action in the database. The follow up coordinators have received training regarding how to document their actions in the database. Once the database has been upgraded, improved data quality will allow for an accurate analysis of the timeliness of follow-up of infants who fail or miss their newborn hearing screening. Resolving this issue has been temporarily delayed as enhancements to the CCHD and BDRIS modules, and connection of the MD EHDI data system to Maryland's HIE and all state birth hospitals has taken priority. Once the priority enhancements are complete, the database vendor will resume its work on a solution that will allow extraction of this data without including pending appointments.

Goal 2: To increase family/parent involvement in all aspects of the MD EHDI program.

Measures:

- 2.1 The degree to which MD EHDI program ensures family/parent participation in its program and policy activities.
- 2.2 The number of events that included parent participants.
- 2.3 The number of individual parents who participated in MD EHDI in any way within a designated time period.

Objectives:

1. Create a plan for parent involvement in developing and implementing MD EHDI policies and programs within one month of project award notification.
2. Design and implement parent outreach, network, education and training through a sub-grant award to a parent organization within the first quarter of Project Year 1.
3. Ensure parent participation in Maryland's national level EHDI activities.

Results:

At the beginning of the project period, a sub-grant award entitled, "Parent Outreach, Education and Training Activities," was provided to the Parents' Place of Maryland (PPMD) to create a plan for parent involvement in the MD EHDI program. The Parents' Place is a non-profit organization that provides peer support and other services to families of children with any kind of disability or special health care need. It serves as both Maryland's Family Voices and F2F (Family to Family) federal grantee. A parent liaison was hired through the sub-grant award to facilitate program activities under the parent involvement plan. The "Parent Connections" parent to parent mentor program for families of children with hearing loss was launched in May, 2012 and a plan for parent-outreach, networking, and educational activities was implemented. "Parent Connections" has grown to 9 mentors and 28 total parent matches. Accomplishments since the most recent progress report to HRSA for the period 9/1/2013 to 02/28/2014 included training of 3 parents in a 6 Week Special Education LEADers Training with more parent mentors planning to sign up for future sessions. Seven parents attended the Language, Literacy and Deaf Children, Research to Practice Workshop in September, 2013. Five parent mentors attended the Parent Advocacy Training in November, 2013. During this period, Parent Connections have presented at 16 occasions. Parent mentors have planned and hosted 6 regional parent trainings within the above specified reporting period on topics which range from IEP's (Individualized Education Plan) and Your Child to Fun Ways to use ASL (American Sign Language) at Home. The number of participants for each event ranged from 12 – 87.

Parents have been actively involved in the planning of the May, 2014 annual Maryland EHDI Stakeholders meeting. Featured speakers include Christine Yoshinaga-Itano, Ph.D. and Beth

Benedict, Ph.D. HRSA grant funds will be used to send two Maryland parents who have a child with hearing loss and one MD EHDI staff member to the 2014 National EHDI Meeting. A third Maryland parent of a child with hearing loss received an NCHAM stipend to attend the meeting. Two additional MD EHDI staff members received funding to attend the meeting through a separate federal funding opportunity.

Goal 3: To improve access to outpatient infant hearing screening services for parents in targeted, high-need areas or populations of the state.

Measure:

3.1 The percent of infants within each identified jurisdiction that need and receive an outpatient infant hearing screening.

Objectives:

1. Identify jurisdictions and/or populations of greatest need for outpatient screening services prior to the start of Project Years 1 and 2.
2. Purchase Otoacoustic Emissions (OAE) screening equipment within the first quarter of each Project Year.
3. Create outpatient infant hearing screening sites within highest need jurisdictions or populations within the first quarter of each Project Year.
4. Promote use of newly created outpatient hearing screening sites by the end of the third quarter of each Project Year and throughout entire Project period.
5. Monitor newly created outpatient hearing screening sites to ensure access and use by families requiring outpatient services at time of award and throughout the third quarter of each Project Year.

Results:

Purchase of the equipment was not made due to delays caused by state procurement procedures.

Goal 4: To establish a system for maternity center and home-based midwives to report occurrent infant births to MD EHDI.

Measure:

4.1 The percent of maternity center and home births reported to MD EHDI.

Objectives:

1. Educate maternity center and home birth midwives on the MD EHDI processes within the third quarter of Project Year 1.
2. Establish a reporting relationship with Maryland maternity center and home birth midwives within the fourth quarter of Project Year 1 and throughout the remainder of the project period.
3. Promote the practice of infant hearing screening by maternity center and home birth midwives throughout Project years 2 and 3.

Results:

Educational outreach has been extended in the form of site visits to the two birthing centers in Maryland, Special Beginnings Birthing Center and Bay Area Midwifery to teach them about the Maryland Early Hearing Detection and Intervention purpose and procedures. Training on the MD EHDI database has been provided to the staff at both birthing centers. The staff has been very receptive to working directly with MD EHDI. Special Beginnings has expressed interest in conducting follow up hearing screens if funding would be provided for the screening equipment.

Goal 5: To increase provider participation within the MD EHDI program.

Measure:

5.1. The annual LTF/LTD rates of individual practitioners and/or practices who have attended educational sessions or received site visits.

Objectives:

1. Increase contact with PCPs and/or other physicians, and audiologists by the end of the fourth quarter of each Project Year 3.

Results:

There are currently three physician practices that consistently report to the state using the MD EHDI database. Practice 1 has been reporting since April, 2012 and has a LTF rate of 0 (18 cases completed and 1 May, 2013 baby in process). Practice 2 has been reporting since October, 2012 and has a LTF rate of 0 (238 cases completed, 1 June, 2013 and 2 May, 2013, and 1 April, 2013 babies in process). Practice 3 has been reporting since January, 2013 and has a LTF rate of 0 (18 cases completed and 1 June and 2 May babies in process).

The Maryland EHDI AAP Chapter Champion had been very active in her efforts to encourage the use of the MD EHDI database by Maryland's physicians and to spread the message of early hearing detection and intervention and reducing loss to follow up, however she announced her retirement from the Chapter Champion position in November, 2013 due to relocation to another state.

Goal 6: To develop a long-term action plan for MD EHDI that is responsive to the needs of the population served.

Measure:

6.1. The percent of identified activities completed under this goal.

Objectives:

1. Conduct a comprehensive appraisal of the entire MD EHDI process within the first quarter of Project Year 3.
2. Develop a long-term action plan for incorporating the needs identified by the appraisal to form the basis for the future work of MD EHDI within the fourth quarter of Project Year.

Results:

This activity will be conducted during Project Year 3.

Table 15. Glossary of Acronyms

1-3-6 protocol	screening by age 1 month, diagnosis by age 3 months and intervention by age 6 months
AAA	American Academy of Audiology
AAP	American Academy of Pediatrics
AMA	American Medical Association
AMCHP	Association of Maternal and Child Health Programs
ASL	American Sign Language
BDRIS	Birth Defects Reporting Information System
CDC	US Centers for Disease Control and Prevention
CEU	Continuing Education Unit
CME	Continuing Medical Education
CMS	Children's Medical Services
CoC	Maryland Consortium for CYSHCN
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
DHoH	Deaf or Hard of Hearing
EHDI	Early Hearing Detection and Intervention
FSRC	Family Support and Resource Center
HASA	Hearing and Speech Agency
HIE	Health Information Exchange
HRSA	Health Resources and Services Administration
IEP	Individualized Education Plan
LTF/LTD or LTF/D	Lost to Follow-up/Lost to Documentation
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MD AAP	Maryland Chapter of the American Academy of Pediatrics
MD DHMH	Maryland Department of Health and Mental Hygiene
MD EHDI	Maryland Early Hearing Detection and Intervention
MD EHDI	Maryland Infant Hearing Program
MPIP	Maryland Pediatric Improvement Partnership
MSDE	Maryland State Department of Education
MSPH	Master of Science in Public Health
MUA	Medically Underserved Areas
MUP	Medically Underserved Populations
NCHAM	National Center for Hearing Assessment and Management
NICHQ	National Initiative for Children's Healthcare Quality
NIPN	National Improvement Partnership Network
OAE	Otoacoustic Emissions

OGPSHCN	Office for Genetics and People with Special Health Care Needs
PCP	Primary Care Provider
PPMD	The Parent's Place of Maryland
Q1	1st Quarter of the Year
Q2	2nd Quarter of the Year
Q3	3rd Quarter of the Year
Q4	4th Quarter of the Year
QI	Quality Improvement
SSDI	State Systems Development Initiative
UNHS	Universal Newborn Hearing Screening
VSA	Maryland's Vital Statistics Administration
WIC	Women, Infants and Children (Special Supplemental Nutrition Program)