Ohio EHDI Hearing Screening & Follow-up Survey (HSFS)

2011

SCREENING SUMMARY	OHIO	US
Births Reported to EHDI Program	**138,571**	**3,793,158**
Births According to Vital Statistics	**138,571**	
Total Screened	**135,351**	**3,713,502**
Percent Screened	**97.7%**	**97.9%**
Number of Infants Not Screened	**3,220**	**79,656**
**Infants Died*	**803 (0.6%)**	
**Parents/Family Declined*	**265 (0.2%)**	
**Missed*	**1,072 (0.8%)**	
**Unknown*	**1,080 (0.8%)**	

EI SUMMARY	OHIO	US
Total Hearing Loss	**214**	**5,200**
Total Enrolled in EI	**152**	**3,287**
Percent Enrolled in EI	**71.0%**	**63.2%**
Percent Loss to Follow-up for EI	**20.6%**	**25.7%**

1-3-6 Goals for EHDI

Screen by **1** month; Diagnose by **3** months; Early Intervention by **6** months

DIAGNOSIS SUMMARY	OHIO	US
Total Screened	**135,351**	**3,713,502**
Total Non Pass	**4,302**	**59,021**
Percent Non Pass	**3.2%**	**1.59%**
Total Non Pass with Normal Hearing	**2,438**	**28,522**
Percent with Normal Hearing	**56.7%**	**48.3%**
Total Non Pass with Hearing Loss	**214**	**5,118**
Percent with Hearing Loss	**5.0%**	**8.7%**
Total No Diagnosis	**1,650**	**25,381**
**Parents/Family Unresponsive*	**23 (1.4%)**	
**Unable to Contact*	**1,007 (61.0%)**	
**Unknown*	**437 (26.5%)**	
Number Loss to Follow-up for Diagnosis	**1,467**	**20,615**
Percent Loss to Follow-up for Diagnosis	**34.1%**	**34.9%**

PREVALENCE OF HEARING LOSS	
OHIO	**1.6 per 1,000 screened**
US	**1.5 per 1,000 screened**

Ohio and National LTF/LTD Statistics from 2011 CDC Report

	Ohio	National
Screening		
Percent Pass before 1 month of age:	99.2%	97.7%
Percent of Non-Pass identified by one month of age:	95%	83.3%
Diagnosis		
LTF/LTD	34.1%	35.3%
Percent NH+HL by 3 months of age:	83.2%	70.8%
Early Intervention		
Enrolled:	71.0%	62.9%
LTF/LTD	20.6%	26.0%

Screening

Screened before discharge	Screened by 1 month of age	Ohio's % Pass	National % Pass	Non-Pass before discharge	**Ohio's % Non-Pass (identified by 1 month)**	**National % Non-Pass (identified by 1 month)**	Non-Pass before 1 month of age
135,351	129,966	99.2	97.7	4,302	**95%**	**83.3%**	4,109

Diagnostic

Did Not Pass F/U Evaluation	No HL 1 month of age	No HL 3 months of age	No Diagnostic Evaluation	Confirmed HL	Confirmed HL by 3 months	Ohio's % confirmed HL	**Ohio's LTF/LTD**	**National LTF/LTD**
4,302	2,438	2,083	1650	214	124	58%	**34.1%**	**35.3**
Prevalence Rate: **Ohio 1.6 National 1.5**								
Percent of Normal Hearing + Hearing Loss Evaluations by 3 months **Ohio 83.2%** **National 70.8%**								

Early Intervention

HL	*Enrolled Part C	# Eligible	*Non Part C	**Ohio's% Enrolled**	**National % Enrolled**
214	152	158	**unknown**	**71.0%**	**62.9**
# LTF/LTD	Unable to contact	Unknown	**Ohio's LTF/LTD**	**National LTF/LTD**	
44	16	28	**20.6%**	**26.0%**	
*Currently, Ohio does not track the infants enrolled in Non Part C Services.					

NEEDS: Start tracking Non Part C EI Services; Children only receiving monitoring, age of enrollment reported for Early Intervention Services for Early Intervention Service and Start tracking & collecting additional Demographics for Screening, Diagnosis, and Early Intervention: Maternal Age; Education; Ethnicity; Race, and Gender **BARRIERS:** Personnel constraints, financial & Data System limitations **PLAN:** Work with Researchers & Programmers to identify process of collecting demographic/needed data.

UNHS in Ohio
Report to the Legislature

Fall 2013

Ohio Department of Health Infant Hearing Program

The State of Ohio has had a mandate in place since 2004 for **Universal Newborn Hearing Screening (UNHS).** All birthing hospitals, freestanding birthing centers and all of the children's hospitals conduct hearing screenings and report results to parents, the nurse practitioner, nurse midwife, or primary care provider, and the **Ohio Department of Health (ODH)**.

The mandate for universal screening supports the goals of the national Early Hearing Detection and Intervention program. The Ohio newborn hearing screening program is critical for identifying the approximately 425 infants in the state, about three per 1,000, that have a permanent childhood hearing loss.

Screening, diagnosis, and early intervention are all key provisions to providing families with the necessary support for their deaf or hard of hearing infants and toddlers in order to help them build the best possible communications skills during the developmental stage for communications skills development. Ideally, our goal is to identify, diagnose and offer early intervention so that by the time the child with a hearing loss reaches the age of three, his or her communications skills are comparable to those of a child without a hearing loss.

This report highlights activities and data in the three categories of screening, diagnosis and early intervention. It also includes the story of a family helping their child overcome a hearing loss. Their experiences illustrate the importance of early and ongoing monitoring for hearing loss.

According to the *2007 Position Statement of the Joint Committee on Infant Hearing* all infants, regardless of newborn hearing screening outcome, should receive ongoing monitoring for the development of age-appropriate auditory behaviors and communications skills. Any infant who demonstrates delayed auditory and/or communication skills development, even if he or she passed newborn hearing screening, should receive an audiological evaluation to rule out hearing loss.

National Standards for Early Hearing Detection and Intervention

Joint Committee on Infant Hearing 1-3-6 Goals	
1	All newborns have a hearing screening before 1 month of age.
3	Diagnostic audiologic evaluation performed by 3 months of age for babies not passing UNHS.
6	Early Intervention services start before 6 months of age for babies with permanent hearing loss.

1 Screening

Ohio hospitals use **Automated Otoacoustic Emissions (AOE)** and **Auditory Brainstem Response (ABR)** hearing screening methods to test newborns before discharge.

	2009		2010		2011	
	Number	Percent	Number	Percent	Number	Percent
Total Babies Born	145,546	100	139,841	100	138,571	100
Reported Hearing Screenings	140,412	97	136,416	98	135,351	98

Challenge: Reduce the number of missed hearing screenings.

Action: Hospitals in Ohio screen nearly all of the babies born in their facilities. ODH Consultant Audiologists regularly monitor hospital reports and verify documentation for hospital screenings. Many of the remaining two percent of infants are born at home and information about the importance of hearing screening is provided to parents when they register the birth at their local health department.

3 Diagnosis

Newborns not passing UNHS are referred to audiologists for follow-up hearing evaluations. ODH funds nine **Regional Infant Hearing Programs (RIHPs)** to help arrange for prompt follow-up appointments. Audiologists can perform tests to evaluate hearing while very young infants sleep. After 6 months of age, sedation (in a hospital) often is necessary in order to complete the testing.

	2009		2010		2011	
	Number	Percent	Number	Percent	Number	Percent
Total Non-pass Screening Results	4,388	100	4,865	100	4,302	100%
RIHP Follow Up and Tracking						
Diagnostic Evaluations Completed	2,360	54	2,684	58	2,652	62
Lost to Follow-up: Unable to Contact or Unknown	1,953	45	1,788	39	1,444	34
Other: Infant Died, Family Non-responsive, Declined Evaluation or Moved Out of Jurisdiction	75	1	393	3	206	4

Challenges: Reduce lost to follow-up and assure RIHPs obtain and document audiology follow-up/ diagnosis by 3 months of age.

Actions: ODH Consultant Audiologists monitor audiology evaluations provided to RIHPs. Sometimes evaluations cannot be completed in one visit if the infant is awake or hungry. Families may be reluctant to schedule another visit due to lost work time or a long commute to the audiologist's office. Sometimes the phone is disconnected and the RIHPs or Primary Care Provider are unable to contact the family. Protocols have been implemented to ensure additional tracking is done to obtain and document missing diagnostic reports.

6 Early Intervention

Infants diagnosed with permanent childhood hearing loss are eligible for Early Intervention services. The RIHPs provide language and auditory stimulation, informatio89n about communication options, counseling and family support, and interaction with the deaf community. RIHP services are provided in all 88 Ohio counties. Families of infants with hearing loss are enrolled in **Help Me Grow (HMG)**, Ohio's birth to age 3 early intervention program, and may receive assistance with other developmental delays in addition to the hearing loss. (Please visit www.ohiohelpmegrow.org to learn more.)

	2009		2010		2011	
	Number	Percent	Number	Percent	Number	Percent
Number Diagnosed with Hearing Loss	150	100%	183	100%	214	100%
Number Enrolled in EI by 6 Months	65	43%	53	29%	110	51%
Infants and Toddlers, Birth to Age 3, Receiving RIHP EI Services Annually	520		601		580	

Challenge: Ensure infants with confirmed hearing loss receive intervention services by 6 months of age.

Actions: The ODH Consultant Audiologists have worked closely with RIHPs and in coordination with HMG Service Coordinators to ensure referred infants are enrolled in HMG and Individual Family Service Plans include provision for RIHP habilitative services for early intervention. Some infants continue to be identified after six months of age, especially those with serious medical concerns or late onset hearing losses. All deaf or hard of hearing infants and toddlers are eligible for habilitative services up to the age of three after they enroll in **HMG.**

For more information about the Infant Hearing Program, please contact the Bureau for Children with Developmental and Special Healthcare Needs at the Ohio Department of Health at 614.644.8389 or see www.ohiohelpmegrow.org/ (infant link)

Elliot: An Early Hearing Detection and Intervention (EHDI) Success Story

by Elliot's Mom

Elliot was two days old when we discovered that he might have a hearing loss. I'm also hard of hearing and many people in my family are as well, however it never occurred to me that Elliot might have a hearing loss too. When the audiologist screened him at the hospital and told us that he didn't pass the hearing screening, I was devastated. I remember when she came into the room and introduced herself my heart dropped. I was already feeling such a range of emotions after giving birth and this was not the news I wanted to hear. The audiologist explained that some newborns that do not pass the hospital's UNHS will not have hearing loss, especially babies born via C-section, like Elliot. Babies born by C-section can have debris in the ear canals that may affect the hearing screening results. Babies who do not pass the first hospital screening are required to have a second hearing screening before discharge. The second hearing screening would be conducted the following day to allow time for the ears to clear. I hoped that the second hearing screening would indicate pass results; however, I was not terribly optimistic. Needless to say, the second screening produced similar results. The audiologist explained the next step would be to get a more thorough audiologic hearing evaluation.

We called the children's hospital closest to our home and got an appointment where the audiologist conducted an **Auditory Brainstem Response (ABR)** test on Elliot. The audiologist placed electrodes on Elliot's head and then presented soft clicks through headphones. The ABR would tell us how his brainstem responded to the soft clicks. This was quite an ordeal because Elliott needed to be asleep or quiet during the evaluation and he kept waking up. Luckily, we were able to continue with the evaluation. After the diagnostic tests, the audiologist confirmed that Elliot (at one month of age) had a permanent hearing loss. Elliot's hearing loss was a sloping mild to moderate sensorineural hearing loss for the lower frequencies and a moderate to severe sensorineural hearing loss for the higher frequencies. The audiologist charted his hearing loss to give us an idea of what he could hear and what he couldn't hear. His hearing loss seemed to be similar to mine.

We were referred to Ohio's HMG early intervention program and made an appointment right away. HMG performed assessments to see how Elliot was developing. HMG referred Elliot to the **Regional Infant Hearing Program (RIHP).** The next step was to go to the hearing clinic, where we saw the ENT doctor, a speech pathologist, the audiologist, and a nurse practitioner. The speech pathologist was confident that since Elliot would be getting his hearing aids so early, he shouldn't have language delays, which was a big relief for us. When we met with the audiologist we were tickled by the different color options. We chose beige hearing aids and blue ear molds. Next, we had our first appointment with the RIHP parent advisor, who came to our home and conducted a test to obtain a baseline language development score. We were thrilled that they would be coming to our home for the appointments. The RIHP parent advisor was wonderful. She gave us some pointers and reiterated what the speech pathologist at the hospital had said; since Elliot would be getting his hearing aids so early, he shouldn't have language delays.

Elliot's hearing aids finally arrived at 4 months of age. We were anxious to see how he would do with them and relieved that he didn't mind wearing them. The audiologist told us that the more he wore them, the better. We made sure he wore them most of the day and took them out when he slept. Due to the RIHP parent advisor's help, support, and habilitation services, by the time Elliot had his hearing aids for three months; his language development had improved significantly. The parent advisor came to our home and conducted a second language development assessment. Elliot's expressive language development score was within the 6-8 month range and his receptive language development score was within the 4-6 month range.

I wrote this story when Elliot was nine months old and had his hearing aids for about five months. We see the audiologist once a month and the RIHP parent advisor comes every other week. The RIHP parent advisor develops lesson plans, models and reinforces activities for developing Elliot's auditory, language and communication skills. We've learned so much throughout this process. Every time the RIHP parent advisor comes she gives us tips and information for Elliot and teaches us something new to try with him. I am finally coming to terms with Elliot's hearing loss and my husband and I are grateful for all the help we've received. I often wonder how his hearing loss compares to mine. I know that if I'm not wearing my hearing aids, there are certain sounds I can't hear. I also rely a lot on reading lips and contextual clues when someone is speaking. Elliot cannot rely on these things, so it is critical he wear his aids so he's not missing anything.

Even though it was devastating to find out Elliot didn't pass the hospital hearing screening we're so grateful that the UNHS was available so we could follow-up with an audiologist. If not for the UNHS at the hospital we probably wouldn't have known about his hearing loss until he was older and his language was delayed. I often wonder when we would've discovered Elliot's hearing loss and how much sound and language he would've missed. We are fortunate he was diagnosed early and that we were connected with Ohio's early intervention resources HMG and RIHP. I just don't know what we would've done without the early help and support. With their continued help, support, and education, I'm confident Elliot will grow up to reach his full potential in whatever he chooses.

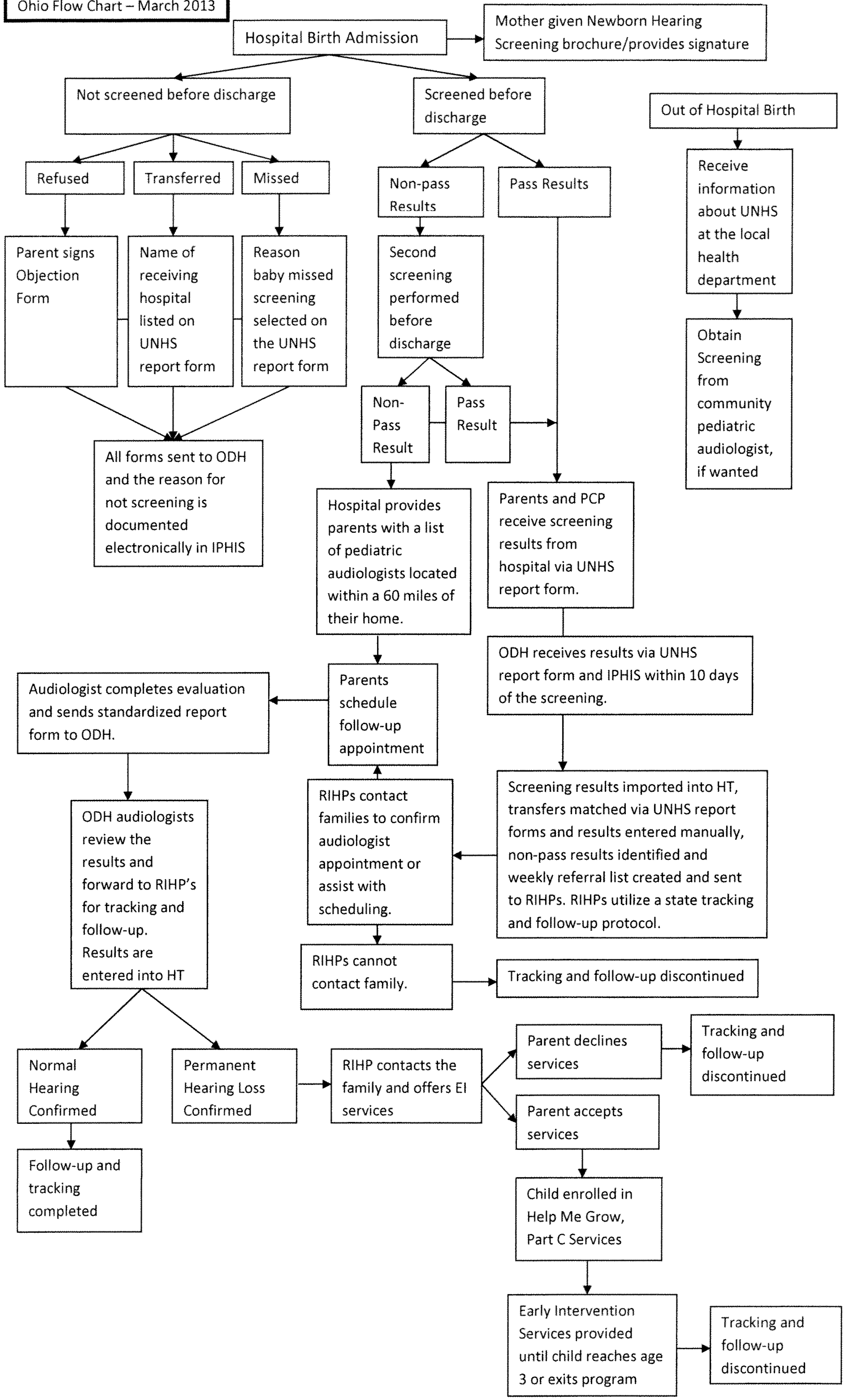
Ohio's **Early Hearing Detection and Intervention (EDHI)** Goals are **0/3/6**. Screen at **Birth**; Diagnose by **3 months**; Early Intervention by **6 months**. Elliot's parents ensured he met and exceeded the national EHDI goals of having his hearing screening completed before hospital discharge, was diagnosed at 1 month of age, and started EI at 2 months of age.

Elliot's story and EHDI research supports that when infants with hearing loss receive timely and appropriate screening, diagnostic, and intervention services, they have positive speech, language and listening developmental outcomes similar to their hearing peers.

Ohio
Department of Health

Attachment 5

Ohio Flow Chart – March 2013



Title: **Reducing Loss to Follow-up in Ohio**
Organization: Ohio Department of Health
Address: 246 North High Street, Columbus, OH 43215
Project Coordinator: Naomi Halverson
Contact Phone Number: 614-644-8389 Fax: 614-728-9163
Contact Email: naomi.halverson@odh.ohio.gov
Web Address: www.ohiohelpmegrow.org/parents/infanthearing/infanthearing.aspx
Funds Requested: $250,000

Reducing Loss to Follow-up in Ohio **December 2013**

Introduction

Then Infant Hearing Program within the Bureau for Children with Developmental and Special Health Needs at the Ohio Department of Health is applying for grant funding under this announcement in order to continue activities strengthening early identification of infants who are hard of hearing and offering their families early intervention services in accordance with the national Early Hearing Detection and Intervention guidelines of completing hearing screening by one month of age, diagnosis by three months of age, and enrollment in early intervention by six months of age. The program staff was oriented to the National Initiative for Children's Health Quality Model for Improvement in 2011 and has successfully utilized it to test small changes, to assess their effectiveness, and to implement promising initiatives that have begun to reduce the state's lost to follow-up/lost to documentation. The Program is seeking funding to continue to use the National Initiative for Children's Health Quality Model to enhance coordination of activities for assuring that families of newborns who do not pass a hospital hearing screening promptly receive and keep appointments for further evaluation, for assuring that diagnostic evaluation of non-pass infants is completed and documented, and for assisting families of children identified with a permanent hearing loss with linkages to early intervention services.

Some of the recommended changes for improving follow-up have been implemented in

Ohio for a number of years, including ascertaining the name of the infant's primary care provider and obtaining a second point of contact for the family. The Program continues to seek ways to strengthen tracking of referred infants and under new rules, effective November 12, 2013, the hospitals are being asked to 1) assist families with scheduling a follow-up appointment, 2) provide the families with written screening results, and 3) notify the primary care provider within 48 hours of discharge when the infant had a non-pass hospital screening. Between 97% and 98% of newborns are consistently screened each year in Ohio.

In 2011 there were 4,303 infants who did not pass a newborn hearing screening. Once these infants are referred for further evaluation, the nine Regional Infant Hearing Programs in Ohio initiate follow-up protocols to assist and track families of non-pass infants with scheduling and follow-up appointments. Approximately 66% of the infants that do not pass the hospital screening receive a diagnostic evaluation. Ohio has worked hard to reduce the lost to follow rate from a high of 45% in 2009 to 34% in 2011. Some families are lost to follow-up when families do not follow through with appointments or are lost to documentation when the Ohio Department of Health does not receive diagnostic evaluation results. Some families do not keep their appointments, and some families do not follow through when diagnostic results are inconclusive and repeat appointments are necessary. Within the new rules previously mentioned, Ohio is now requiring audiologists to report the diagnostic hearing evaluation results to the Ohio Department of Health within seven days of confirmation of an infant's hearing status in order to remove one of the barriers to obtaining results.

In addition to tracking and follow-up, the Regional Infant Hearing Programs provide early intervention services to infants and toddler with a confirmed hearing loss. They contact the families of these infants to offer assistance with enrollment, assist with linkages to Help Me

Grow, the Ohio Part C Early Intervention Program, and assure that Regional Infant Hearing Programs Early Intervention services are included in the Help Me Grow Individual Family Service Plan. In 2011 about 70% of the infants that were identified with a hearing loss were documented as enrolled in Early Intervention. Some of the remaining 30% of infants may be receiving early intervention through private insurance. Some families may decline services thinking that their infant does not need them, but some also continue to be Lost to Follow-up/Lost to Documentation.

Our objectives under this grant will be to reduce lost to follow-up and lost to documentation through improved coordination at each of the transition points: from the hospital to diagnostic services and from diagnosis to enrollment in early intervention. Our aim is to reduce Lost to Follow-up/Lost to Documentation by 5% annually for the next three years through the identification, testing, and implementation of small changes as identified with the help of stakeholders in each of the transition points and then utilizing the National Initiative for Children's Health Quality Model for Improvement to test the changes, implement them, and expand or institutionalize the ones that help reduce Lost to Follow-up/Lost to Documentation.

Organizational Information

The Ohio Department of Health is a cabinet agency, and the director reports to the governor. The Ohio Department of Health is organized by three program divisions and six offices. Program divisions are the Division of Family and Community Health Services; Division of Prevention; and Division of Quality Assurance. The offices are Employee Services; Financial Affairs; Management Information Systems; General Counsel; Performance Improvement and Healthy Ohio. The mission of the Department is to *Protect and Improve the Health of All Ohioans by Preventing Disease, Promoting Good Health, And Assuring Access to Quality Care*.

Strategic goals that directly apply to the INFANT HEARING PROGRAM include *assuring quality and safety of health care services* and *eliminating health disparities.*

The Infant Hearing Program is a small unit within the Division of Family and Community Health, Bureau for Children with Developmental and Special Health Needs. The Infant Hearing Program is part of Ohio's Part C Early Intervention Program, and is housed in the Genetics Section. In addition to the Infant Hearing Program, the Genetics Section includes Genetics Services, Sickle Cell Services, Ohio Connections for Children with Special Needs (OCCSN birth defects information system), and Metabolic Formula Programs.

One of the greatest strengths of the Infant Hearing Program is the dedicated, knowledgeable staff. The three public health audiologists each have between 6 and 12 years of experience with the Ohio Infant Hearing Program. All of them have either a Ph. D. or a Doctor of Audiology degree. Each of them has been involved with the National Initiative for Children's Health Quality Learning Collaborative and has an understanding of the Model for Improvement and its application. They share a dedication to providing timely, appropriate services to families of infants who are deaf or hard of hearing and they have a passion for ensuring that quality services are available and accessible to all infants that need them. They are supported by a part-time data entry operator and a college intern. The program supervisor and section supervisor have a broad range of public health program knowledge and experience.

In addition to program staff, there are many knowledgeable people within the public health sector and within Ohio Department of Health that the Infant Hearing Program can contact for assistance as needed. Among them are colleagues within the Bureau for Children with Medical Handicaps, Ohio's Title V Children with Special Health Care Program; Vital Statistics; and Medicaid; as well as various individuals who can provide information technology support, epidemiological support, and fiscal, grant, and contract management support.

Needs Assessment

The 2009 estimated population of Ohio was 11,542,645, giving the state a population density of 282 people per square mile. Ohio ranks as the seventh most populous state among the 50 states and the District of Columbia.

An estimated 81% of the population in Ohio resides in metropolitan areas. The ten counties with the largest populations are Cuyahoga, Franklin, Hamilton, Montgomery, Summit, Lucas, Stark, Butler, Lorain and Lake. Ohio’s 88 counties are categorized as metropolitan (11), suburban (16), rural non10 Appalachian (29) and Appalachian (32).

The population of Ohio is becoming more diverse. The Hispanic population, composed mainly of persons of Mexican and Puerto Rican origin, has grown 22% since 2000. The Black population has grown 5.6%. The three largest groups of Asian populations in Ohio are of Indian, Chinese and Vietnamese origin. In 2008, 86.6% of the population was white, 8.0% was black, 0.8% was Asian and 1.6% was Native American and Alaskan Native. These groups also include Hispanics who made up 2.3% of the population.

In keeping with national trends Ohio's population is aging. Ohio births have declined from the baby boom high of about 243,000 in 1957 to just over 138,000 in 2011. In 2008, the population of children through age 24 was 3,812,111, representing 33% of the total population. Growth in the under age 18 cohort gained only 3.2% and is concentrated in areas of greater population density.

Females in Ohio accounted for 51.2% of the total population in 2008. Twenty-five to 64-year-olds make up 52.6% of the female population and according to Ohio Department of Health

Vital Statistics in 2010 the fertility rate for women between the ages of 15 and 44 years of age was 62%. There were 148,592 live births to Ohio residents in 2008. By mother's race, births were distributed as follows: white, 75.7%; black, 15.9%; all other races, 8.4%.

The Ohio resident live birth rate decreased over the period 1994 to 2008, from 14.3 births per 1,000 to 12.9 per 1,000. The white rate followed this pattern, but the Black birth rate declined until 2003, at which point it increased from a low of 16.1 births per 1,000 to a low of 18.1 in 2008.

In 2008, Hispanics experienced the highest live birth rate of all racial/ethnic groups examined, and this was the only group with a marked increase across the period. The Hispanic population continues to represent an increasing proportion of Ohio births over time. While the proportion of all births that were Hispanic increased 2.7 fold between 1994 and 2008, Hispanics still represented only 4.6% of all Ohio live births in 2008.

Ohio has 4,508,871 total households with 16.8% being are single-parent households. In 2008, the Ohio Department of Health reported approximately 33.8% of the single-parent households were female householders, excluding single women who live with the child's father and single teenage moms who live with a parent or other relative.

The percentage of births to single mothers has increased from 34% in 1997 to 43% in 2008. The number of single mothers in Ohio has increased to 704,965. In Ohio, 78% of all births Black mothers were to single mothers, whereas 36% of all white births were to single mothers according to 2008 records.

According to the 2005/2006 National Survey of Children with Special Health Care Needs (CSHCN), the total number of children with special health care needs under the age of 18 in Ohio was 445,205 or 16%. The survey identified 381,667 Ohio households with children with special health care needs or 23.9% of the state's households. Nationally, 21.8% of all households had a child with a special health care need.

In 2008, 13.3% of Ohioans were living below the federal poverty level. This is similar to the national rate of 13.2%. The poverty level; however, varies greatly by county. The five counties with the highest poverty rates were Athens (29.6%), Vinton (23.0%), Adams (21.9%), Morgan (21.1%) and Jackson (20.7%). The five counties with the lowest poverty rates were Delaware (4.9%), Medina (5.8%), Warren (6.6%), Geauga (6.9%), and Union (7.1%). Within metropolitan areas, the average poverty rate for Ohio cities was 18.9%, compared to 6.5% for areas outside of the central cities. Eight central cities had poverty rates greater than 20%: Cleveland (26.3%), Bowling Green (25.3%), Kent (25.2%), Youngstown (24.8%), Dayton (23.0%), Lima (22.7%), Cincinnati (21.9%) and Steubenville (20.4%). The counties with the highest poverty rates are located in Appalachian Ohio. Two-thirds of Ohio's poor are white, yet this racial group has the lowest poverty rate--10.8% in 2008. The poverty rate was 29.3% for Blacks, 12.3% for Asian and 24.8% for Hispanics.

Although not generally considered a minority group, residents of Appalachian counties differ from other Ohioans. The rural areas of Ohio that are included in Appalachia encompass 33% of the counties bordering the Ohio River on the east and southeast section of the state. They are more isolated, economically distressed areas with poor support services. They tend, in general, to have a higher percentage of residents living at or below the poverty level, higher unemployment rates and fewer job opportunities along with lower education levels and fewer educational opportunities. Residents of Appalachia may lack personal transportation and public transportation is limited or non-existent.

Families with children are at greater risk of being poor than families with no children and the risk among families headed by a woman with no spouse present is much larger. Those with at least one child had poverty rates three to ten times higher than the rates of those with no children. The age groups characterized by higher-than-average poverty rates are children (ages 0 to 17 years). The higher poverty rate for children may be partly explained by the larger proportion of one-parent families. Of children und 18 years of age 18.5% lived below the poverty level in 2008. The poverty rate for the total population decreased from 1994 (14.2%) through 2008 (13.4%). Overall, the rate for children under 18 years decreased from 1994 (20.9%) through 2008. Of the 2,936,172 families currently estimated to be below the poverty level, 48.5% of those families have related children younger than 18 years of age.

Like many other states, Ohio suffers from a shortage of primary care, dental care and mental health care providers, as well as a lack of pediatric audiologists in a number of rural communities and counties. Attempts at enumerating shortage areas center on those that have gone through the process of being designated a federal Health Professional Shortage Area (HPSA). The data; however, does not present the whole picture because many areas that might qualify as HPSAs do not apply. They include much of rural Ohio and parts of every major city in Ohio (Cleveland, Cincinnati, Toledo, Columbus, Dayton, Youngstown, Akron and Canton).

Medical resources of all kinds are more limited in rural areas, but particularly so in Appalachia. There are fewer primary care providers (PCPs) and they have been reported as more conservative, adopting a wait and see attitude about hearing screening and follow-up hearing evaluation. Parents may not fully understand the need for additional hearing testing or have the resources for immediate follow-up without the support of the PCP. Audiological services are very limited in these areas and while the newborn was screened, follow-up post-discharge may require considerable travel to an urban area, which is both an economic and a logistical barrier for some families.

Ohio has approximately 80 self-reported pediatric audiology providers on the Infant Hearing Program's Pediatric Audiology Services Directory, however they are not represented in many of the rural non Appalachian counties and rural Appalachian counties. The majority of diagnostic audiology evaluations are conducted at the major children's hospitals in the larger metropolitan areas (Cleveland, Cincinnati, Toledo, Columbus, Dayton, Youngstown, Akron and Canton) and many of the pediatric partners we will approach to help reduce our Lost to Follow-up/Lost to Documentation rates for diagnosis will be drawn from these large pediatric audiology centers.

There are several special and distinctive populations of note in Ohio. The migrant population continues to slowly increase. Between 2003 and 2004, this population increased by 4%. Ohio is also home to the nation's largest concentration of Amish. Ohio has also experienced an influx of immigrants, both from primary resettlement of refugees as well as secondary migration from other states. Ohio has large numbers of Amish, Somali refugee, migrant and seasonal workers and the group of Appalachians previously discussed.

Within ODH the Bureau for Children with Medical Handicaps (BCMH) provides financial assistance for eligible families when infants require diagnostic evaluation following the newborn hearing screening. BCMH also covers treatment services such as hearing aids, cochlear implants, and/or other devices. Challenges include linking the family to the BCMH program and assisting them with the necessary documentation for reimbursement and/or enrollment with a certified provider within the required timeframes.

For those infants that are diagnosed with a permanent hearing loss, early intervention services are available in all 88 counties in Ohio. The HMG early intervention program serves approximately 14, 000 children in the state annually. Families of infants and toddlers with hearing loss or deafness are presumptively eligible for Part C services however; they must be enrolled in the HMG program in order to receive early intervention services for these children at no charge to the family through the Regional Infant Hearing Programs.

This brief needs assessment identifies general characteristics and needs for Ohio's families. Further statistical information is available on follow-up with families of infants that do not pass a hospital hearing screening is outlined in the Centers for Disease Control report in the attachments. The Program initiatives under this grant funding will be directed to reaching the infants who were lost to follow-up after numerous attempts to contact the family were unsuccessful or who were still awaiting a diagnosis after three months of age.

Methodology

The Infant Hearing Program in Ohio began working with the National Initiative in Children's Health Quality Model in March, 2011. The Universal Newborn Hearing Screening Advisory Subcommittee was asked to develop work groups focusing on screening, diagnosis, and early intervention. These work groups provided recommendations for quality improvements. Some members helped staff in an Ohio Department of Health National Initiative for Children's Health Quality Team and worked with the Infant Hearing Program to identify specific partners and processes, to write up Plan-Do-Study-Act proposals, and to generally guide the implementation and assessment of the initiatives. Some Plan-Do-Study-Act proposals were carried out by Subcommittee members.

Among the initiatives tested using the National Initiative for Children's Health Quality Model were collaborations with two hospital partners on reducing the number of infants lost to follow-up evaluation. One hospital tested a semi-scripted message for parents of non-pass newborns and the other tested a semi-scripted message for all newborns. Parents were then given a brief survey to see if they understood the results and the next steps. This helped identify screeners that needed more training and documented parents had a better understanding of next steps. The Infant Hearing Program has included a continuation of this process in the grant work plan and will continue to explore improvements in messages to parents of newborns.

Another initiative was developed around providing physicians with a letter as soon as the Regional Infant Hearing Program was aware of the referral. Physicians were notified that their patient did not pass the hospital screening and were requested to refer the infant for further evaluation. A second Plan-Do-Study-Act proposal had the Regional Infant Hearing Programs contact pediatric audiologists and make requests for a copy of the diagnostic evaluation rather than waiting for results to come through the Ohio Department of Health. Over a period of several months, this Plan-Do-Study-Act proposal was expanded to all of the Regional Infant Hearing Programs and has become a standard protocol.

The Public Health Audiologists also expended a great deal of time and effort checking enrollment dates for Early Intervention, verifying data, identifying date discrepancies, and documenting the outcomes as a part of a National Initiative for Children's Health Quality data collection initiative. This documentation was used to identify additional training needs for Regional Infant Hearing Program staff, for Help Me Grow Service Coordinators, and for stronger linkages with better coordination between the two groups. A regular protocol for Ohio Department of Health data comparisons was developed.

The project's objectives will be carried out by the three Infant Hearing Program Public Health audiologists with the assistance of a Public Health Researcher, a part-time Data Entry Clerk, a College Intern, and a Hearing Program Supervisor under the direction of the Genetics Section Administrator. The Infant Hearing Program staff will engage additional stakeholders both internally and externally in developing plans for change, implementing changes, assessing the outcome of the changes and, when applicable, institutionalizing those with promising outcomes.

The Universal Newborn Hearing Screening Advisory Subcommittee of the Medical Advisory Committee, composed of about twenty-five stakeholders in key areas related to infant hearing, meet quarterly to offer advice and recommendations related to program policies and direction. A complete list of subcommittee member roles is included in the Attachments.

As part of the Subcommittee's Infant Hearing Program oversight under the initial Health Resources and Services Administration National Initiative for Children's Health Quality Learning Collaborative project, members of the Subcommittee were asked to participate in three work groups---Screening, Diagnosis, and Early Intervention. These work groups offered suggestions for activities in each of the topic areas. Some members also continued to serve on an Ohio Department of Health National Initiative for Children's Health Quality Team, and some of them were also direct participants in Plan-Do-Study-Act cycles.

The Infant Hearing Program and its partners did not have the resources to continue to sustain all of the ongoing quality assurance activities at the end of the Learning Collaborative. The Subcommittee assisted in determining which projects should be continued given the available manpower.

The Universal Newborn Hearing Screening Advisory Subcommittee members were asked at the November, 2013 meeting to reconvene in the three work groups to review previously proposed activities for change and to consider new initiatives as they related to the best practice goals in the *Supplement to the JCIH 2007 Position Statement* released on July 26, 2013. If the Infant Hearing Program could only move forward with a few activities, what would this group of stakeholders recommend that the Ohio Department of Health do?

These work group recommendations were reviewed by program staff in preparation for this grant application and several of them were chosen for inclusion in the work plan. In addition, initiatives that showed promise when tested under the National Initiative for Children's Health Quality Learning Collaborative were chosen for replication and expansion to additional facilities. The program will continue to work with a small Parent Focus group trying to improve screener messages. Staff will continue to work with hospitals and utilize scripted messages for those identified with high referral rates. Staff will also continue to coordinate with children's hospitals to ensure all diagnostic reports are provided to the Ohio Department of Health during periods of transition to electronic recordkeeping.

The Infant Hearing Program Supervisor/Early Hearing Detection and Intervention Coordinator will invite one or two key stakeholders from each of the Subcommittee work groups to be a part of the "Lost to Follow-up/Lost to Documentation Team" for this HRSA 14-006 funding opportunity. Key members will include a hospital nurse, a pediatric audiologist, and an early intervention provider since our focus is the transition from hospital screening to diagnostic evaluation and from diagnosis to early intervention enrollment. The Public Health Researcher will serve as the data advisor and the Infant Hearing Program will be seeking additional representation on the Team from parents of infants or toddlers who are deaf or hard of hearing. The Ohio Part C Early Intervention program administrator has been asked to join the Team. The Ohio American Academy of Pediatrics Chapter Champion/National Initiative for Children's Health Quality Consultant and Development Pediatrician has graciously agreed to participate. Other members will be included as needs are identified.

The Early Intervention services of the Infant Hearing Program are funded by the Ohio Part C Early Intervention program, Help Me Grow. Help Me Grow is housed in the same Bureau, as are the Home Visiting program. All of the program staffs are located within the same wing of the building and as needs are identified colleagues in these programs can be easily consulted or asked to participate in select initiatives.

A teleconference or web conference will be convened to bring this group together. It is anticipated that they will meet monthly thereafter. They will be briefed on the Subcommittee's background work, and will review the aims, objectives, and proposed activities. They will be asked to help determine if we have the right partners to address our proposed initiatives and to assist in outlining or updating Plan-Do-Study-Act proposals as needed. This Team will serve as a guiding committee and offer feedback, make recommendations, and brainstorm on various approaches to the activities, processes, and measurement and ways to overcome barriers to any of them.

The Infant Hearing Program would like to begin with no more than one or two small tests of change in each of the three areas. A Public Health Audiologist will provide coordination for Plan-Do-Study-Act proposals in each of the specific areas of screening, diagnosis, and early intervention.

The nurse manager, audiologist, early interventionist, or other individuals providing the test of change under a Plan-Do-Study-Act proposals will report on progress monthly or at the next web meeting or teleconference of the Lost to Follow-up/Lost to Documentation Team. The Lost to Follow-up/Lost to Documentation Team will consider the results of the Plan-Do-Study-Act proposal implementation, data collected, the difficulty of administration, outcomes, recommendation for continuing a test or revising a test, and so on. They will be asked to offer suggestions to the implementing subgroup for next steps and help determine whether to revise the Plan-Do-Study-Act proposal, continue with another test cycle of it, expand it, or abandon it and try something else altogether.

The recommendations of the smaller, implementation teams and the Lost to Follow-up/Lost to Documentation Team will drive the Quality Improvement plans. The Infant Hearing Program staff will serve as facilitator, information gatherer, Plan-Do-Study-Act proposal coordinator, and provide a forum for regular meetings. They will assist in identifying and soliciting additional stakeholders to expand promising initiatives and seek ways to institutionalize them while being mindful of the need to continue to engage stakeholders in the process, keep track of outcomes and keep the Follow-up/Lost to Documentation Team apprised of the ongoing and changing initiatives.

Successful tests of change will continue to be replicated. If the change was successful, can we continue to do it for a longer period of time or can we expand the process to other facilities? If those additional expansions are successful, can we expand the timeline to cover a quarter of the year, a region of the state, more facilities, more early intervention providers? For each step, the Follow-up/Lost to Documentation Team will consider how or if to expand the initiative, maintain accountability, and ultimately, institutionalize the change, incorporating them into the routine ways in which the screening, diagnostic, and intervention providers coordinate with the Ohio Department of Health and each other to reduce Follow-up/Lost to Documentation. Upon the conclusion of the grant, our partners will be encouraged to continue those initiatives that produce positive changes. We are all dedicated to the same goals and the Infant Hearing Program staff will continue to provide as much support as possible in continuation and testing of current initiatives. It is the Infant Hearing Program goal to institutionalize changes that positively impact Follow-up/Lost to Documentation, whether through practice, policy, protocol, rule, or some combination thereof so that these positive changes remain in place.

Challenges

The Infant Hearing Program continues to be challenged by the complexity of interfacing between multiple data bases, including Integrated Perinatal Health Information System, Hi*Track, and Early Track. The program extracts basic demographic data from the Vital Statistics Integrated Perinatal Health Information System (electronic birth records). Hospitals have ten days to complete this information but there is no mandate for them to complete the Integrated Perinatal Health Information System-Hearing Screening page within the same timeline. Local boards of health have up to a year to enter birth records for home births. It is difficult to find a balance between extracting information in a timely manner versus extracting complete file information.

After being extracted from the Integrated Perinatal Health Information System, the information is imported into the Hi*Track data base used only by the Infant Hearing Program. Hi*Track is used to generate referrals for non-pass infants, provides space for notes on tracking and follow-up, includes screens for documenting hearing evaluation results, and provides a way to document enrollment in early intervention. There are numerous information technology challenges in moving data from the Integrated Perinatal Health Information System into Hi*Track because the two systems are not perfectly compatible and the Infant Hearing Program sometimes does not have all the up-to-date information needed to easily follow referred infants.

Once the infant is enrolled in Help Me Grow, the Infant Hearing Program staff must then go to a third data base to obtain information on the Individual Family Service Plan for the infant, to track Early Intervention progression, and to document Language Development Scale scores of a child’s progress while enrolled in Early Intervention. The Infant Hearing Program does not have access to this database and must rely on state level Early Track managers or Regional Infant Hearing Program staff working with Help Me Grow Service Coordinators to make corrections to records, document Regional Infant Hearing Program Early Intervention services, and update Language Development Scale scores.

Another of the more difficult challenges is the lack of ongoing Information Technology support. The program does not have dedicated Ohio Department of Health Office of Information Management Service support and had used approved carryover funding from Centers for Disease Control to hire a contractor to work on some of the data base problems last year. The Office of Management Information Systems has limited time to supervise the contractors. Three contractors, with varying capabilities, have attempted to work on some of the data management concerns in the last nine months but without making much progress in resolving any of the most persistent problems. The Infant Hearing Program has budgeted funds in this grant application for dedicated Management Information Services support for providing the necessary technical oversight and is seeking additional funds to hire another contractor. Delays in resolving technology issues may also be caused in the coming year by major revisions currently being planned and implemented by the Office of Management Information.

Another challenge for the program has been the changes in the Public Health Researcher position assigned to the Infant Hearing Program. In January, 2012 a full-time researcher with intimate knowledge of the program retired. The position was filled in April, 2013 but it took several months to orient the new researcher to the complexities of the program.

In October, 2013 the new Researcher moved to another position. Although he continues to provide limited support, he is transitioning into a new position, and the researcher position for the program is currently vacant. From a practical standpoint, this limits the program to the data and data analysis staff themselves can easily generate and examine quickly.

Funding for tracking and follow-up through to Early Intervention as funded by Part C may no longer be available after the 2015 state fiscal year. The Regional Infant Hearing Programs may become private providers, funded through the Department of Developmental Disabilities, and this may make coordination more challenging in future years. Currently the Regional Infant Hearing Programs provide tracking, follow-up, and early intervention for infants and toddlers as subgrantees of the Ohio Department of Health funded primarily by the Part C program and operating under same guidelines. There are strong connections at the State level and staffs of Help Me Grow and the Infant Hearing Program are able to work together to resolve situations involving partners in both programs or to coordinate on issues at the local level.

Evaluation

The IHP will coordinate closely with the Lost to Follow-up/Lost to Documentation Team to reach out to additional hospital partners, audiologists, families, and early interventionists who have been identified as meeting criteria identified in the work plan and who might be willing to work with the Team to improve follow-up, tracking, or early intervention as identified under each aim and objective. Once these partners agree to participate they will have a voice in helping design a Plan-DO-Study-Act proposal and then in implementing it, revising it, adjusting it to fit their needs, and institutionalizing it. At that point it may be offered to others in similar circumstances to promote more positive change and to to incrementally begin to reduce the Ohio Lost to Follow-up/Lost to Documentation rate.

For example, for Objective 1.1, Infant Hearing Program staff and the Public Health Researcher will use data from the Integrated Perinatal Health System and Hi*Track to determine baselines. Data can be obtained in the Integrated Perinatal Health Information System about hospitals with a high referral rate. Once we identify those hospitals, the program can utilize data from Hi*Track about the number of referred families from these facilities that fail to follow through with appointments for diagnostic evaluations. If staff identify a facility with a high referral rate and a high follow-up rate, and determine there are no confounding factors, perhaps this is a hospital that needs assistance with the message they provide to families.

If the hospital identified above is willing to try it, program staff, parents, and other Team members will work with that hospital to develop a new script to use with parents or revise an existing script, provide training to staff using it, and then test it on the next 10 newborns. The hospital partner will obtain parent feedback and provide parent and hospital staff feedback to the Ohio Department of Health staff and Lost to Follow-up/Lost to Documentation Team.

The script can then be revised if necessary, the number of test cycles or the number of parents counseled can be adjusted, and the hospital staff can try the Plan-Do-Study-Act cycle again. This process can be repeated until a script is implemented that provides good parent understanding and follow through.

The Infant Hearing Program staff can monitor tracking documentation entered into Hi*Track by our Regional Infant Hearing Programs to track the families that received the new or revised scripts to see if the number of families following up with diagnostic appointments increases. If data clearly indicates this to be true, the Plan-Do-Study-Act process will be continued at the first hospital with less intensive data monitoring and the Lost to Follow-up/Lost to Documentation Team will invite other high refer/high lost to follow-up hospitals to partner with the Team to try this script and the process will begin anew.

The Public Health Researcher and Infant Hearing Program staff will explore options for obtaining data for families with English as a second language and create a baseline for these groups in hospitals as well. Use of Spanish language materials can be tested in a similar manner in hospital PDSAs with outcomes tracked to determine if more families with Spanish as a primary language are following through with diagnostic appointments after the receipt of revised materials. The same can be done with additional materials about how to apply for financial assistance to cover the cost of diagnostic evaluation when the family's insurance plan does not cover it or the family is uninsured.

Simultaneously, the Infant Hearing Program audiologists will use data available to the Regional Infant Hearing Program and the network of the Lost to Follow-up/Lost to Documentation Team to invite identified pediatric audiology partners to work with the Program to develop Plan-Do-Study-Act proposals, to test, revise, and retest with them to ensure that all diagnostic audiology reports are tracked from family appointment to receipt and review by the Infant Hearing Program and from the Program to documentation by the Regional Infant Hearing

Programs.

There are multiple opportunities for various partners at all levels of the process to work on small changes, document, them, and implement those that will improve reporting and documentation of diagnostic audiology reports from facilities, the Regional Infant Hearing Program, and the Ohio Department of Health. It is the Infant Hearing Program plan to continue to follow this process with each of the proposed aims and activities and to work with the Public Health Researcher to ensure documentation is periodically checked and analyzed. By working together and testing these small changes each of us can play a part in improving the rates of Lost to Documentation/Lost to Follow-up.

Grant Number: H61MC00029
Grant Title: Reducing Loss to Follow-up in Ohio
Organization Name: Ohio Department of Health
Grant Period: April 1, 2011 to March 31, 2014

Summary Progress Report

The Infant Hearing Program (IHP) at the Ohio Department of Health (ODH) currently maintains the Early Hearing Detection and Intervention (EHDI) program in the state. The IHP continues (1) to ensure that Universal Newborn Hearing Screening (UNHS) is performed in Ohio, (2) provides follow up coordination efforts for ongoing tracking and surveillance of babies that need follow up evaluation after a non-passing hearing screening, and (3) provides a grant funded program to offer home-based, specialized early intervention services to support the development of communication and language and also ensures enrollment in the Ohio Early Intervention program.

The IHP has focused on meeting the JCIH EHDI 1-3-6 goals since the passage of Universal Newborn Hearing Screening, almost 10 years ago. More recently, the IHP program participated in the National Initiative for Children's Health Quality (NICHQ) learning collaborative for a special 15 month project from April 1, 2011 – September 5, 2012.

The IHP program developed specific aim statements for Ohio in this reporting period. IHP staff, along with the Team Lead, participated in monthly calls with a team of stakeholders on the NICHQ core and extended team. The NICHQ project was shared with the Infant Hearing Screening Advisory Committee and three workgroups were also created to assist in quality improvement initiatives. The state team, in addition to the three workgroups was a tremendous way to engage stakeholders with Ohio's QI efforts and PDSA cycles. NICHQ state team members, as well as various workgroups helped to develop small tests of change and Plan, Do, Study, Act (PDSA) cycles. The workgroups were an effective way in reaching different parts of the state as stakeholders, and also assisted in building inter-relationships. This has been a great part of the NICHQ work for Ohio. In previous years, the IHP has been less focused on engaging stakeholders and empowering them to assist in meeting the shared values and goals for Ohio's EHDI program.

One of Ohio's major accomplishments with the learning collaborative was that Ohio developed several proven strategies, one which was recognized by NICHQ staff and presented at the 2013 National EDHI Conference. The NICHQ efforts in Ohio assisted with decreasing lost to follow (LTF) and lost to documentation (LTD) rates in Ohio. Initially at the start of the QI process, LTF rates in Ohio were as high as 50% from screening to diagnosis, greater than the national average of 40%. Program participation in the NICHQ collaborative provided staff with the motivation to prioritize a review of the statewide challenges with LTF and LTD and to create a vision of how the improvement process could assist the IHP in meeting some grant goals and objectives more effectively.

Several different PDSA cycles were created and tested. Some of them did not turn out well but others were very beneficial and assisted in significantly decreasing the statewide LTF rates. Among these were improved data reporting from audiologists (LTD issue), improved reliability and validity in two separate data systems for EDHI and EI, increased physician/medical home awareness about EHDI timelines, enhanced access to genetic services and increased screener education. Some of the small tests of change have been sustained and continue to be implemented, a key part of continuous quality improvement.

Ohio has been able to sustain at least two of the several proven strategies and plans to have an implementation phase in the coming months. Improved data reporting for follow up evaluation post UNHS for large, pediatric diagnostic audiology centers has been sustained which is impactful on the LTD rates in Ohio. Additionally, the screener education process has been an exciting process for hospital screeners. We will use this platform to create additional trainings for screeners that emphasize improving follow up rates.

In addition to the NICHQ state team (core and extended members) and Advisory committee workgroups, a Parent-Focus Group (PFG) was also created. The Parent Focus Group consisted of parents of children with hearing loss and a few professionals and was facilitated by the state team lead. The PFG created an innovative process that provided screener education on the screening process, but also touched upon the social and emotional aspects that parents go through with the hearing screening to diagnosis process. This strategy is being sustained in Ohio beyond the NICHQ learning collaborative and is currently being spread.

Another successful PDSA that will be continued in this upcoming grant cycle, is a maternal questionnaire provided by the hospital that provides direct information and feedback to the hospital and the IHP regarding parents' understanding of the results and follow up information. The goal of this strategy was to ensure hearing screening results and follow up information provided to mothers is clear, concise and understandable. Two separate processes for this PDSA included using a semi-scripted message for parents of non-pass infants only and using a semi-scripted message for all infants. A maternal questionnaire or brief survey was provided to mothers after the hearing screening and parent education regarding results and follow up was delivered. Completed surveys were sent to the IHP for review and subsequent feedback was provided to each facility. The survey helped identify hospitals and screeners who needed additional training on delivering UNHS results, next steps for follow up and timelines.

Since Ohio's LTF and LTD rates were high, some of our core team audiology members developed a process to determine if follow up results were reported to the state EHDI program. This cycle allowed the hospital(s) to review the number of results reported as a baseline, provide education to clinical audiologists, reminder cards and standardized forms and then recheck to see if the percentage of reported results increased. The PDSA was very effective in determining that the transition to electronic health records in some of the pediatric diagnostic hospitals was related to the decreased number of follow up results reported to the state. Two larger diagnostic centers in the northern (Cleveland Clinic Foundation) and southern parts (Cincinnati Children's Hospital Medical Center) of Ohio participated. Once audiologists were educated and aware that baseline reporting to the state EHDI program was low, most likely due to electronic health and medical record transitions, and this negatively impacted Ohio's LTF/LTD rates, reporting increased allowing for babies to be appropriately tracked. The impact of this PDSA cycle resulted in a decreased LTF/LTD rate for the state. The NICHQ Project Director asked Ohio to present this particular PDSA cycle and package at the National EHDI conference in April, 2013.

A unique PDSA was created to review enrollment dates from two separate databases to ensure that EI enrollment dates were consistent with the IFSP dates. The goal of this process was to accurately identify the number of EI enrolled infants and children across database systems. The process centered around matching specific criteria between both data systems to show consistency in the number of EI enrolled children. The result was improved EI enrollment dates to match the JCIH goals of enrollment in EI by 6 months of life. Lastly, the program was able to identify and reconcile gaps in reporting enrollment and coding of EI services.

This process outlined discrepancies that existed with Early Intervention enrollment dates between data base systems and allowed for verification of the date of enrollment to be consistent among two data systems for the child. Some of the information regarding refused enrollment is not captured appropriately and the IHP would like to begin looking into the percentages of enrollment versus non enrollment in the state EI and RIHP programs and review potential reasons for refusals. This process will be utilized to develop additional PDSA's to determine potentials reasons for parent/family refusals as this impacts the percentage of enrollment in our program EI impact was measured by reviewing two separate databases with the same children and determining specific variables to review.

A revision to the UNHS rules was approved in November, 2013. Among the revisions that will assist the state EHDI program with LTF/LTD is a requirement for reporting non-pass newborns to the primary care physician within 48 hours. Other changes in the rules will assist in strengthening the EDHI 1-3-6 components.

A Center for Disease Control (CDC) site visit in August, 2013 provided some additional guidance and feedback to the state including a recommendation to create a logic model and streamline data reporting for the program.

Another important accomplishment was an Infant Hearing Program collaboration with the Ohio School for the Deaf in November, 2013 for a statewide EDHI Summit. The Ohio School for the Deaf was the lead agency in planning and hosting a day and a half EHDI Summit. The IHP served on the planning committee, provided an EHDI program overview, provided a display table and shared materials with families and professionals. Direct participation in the EHDI Summit allowed for the extension of collaborative relationships with families and professionals who share the values and goals for decreasing LTF and increased early intervention for babies and children identified with hearing loss or deafness in Ohio.

Goals and Objectives: Progress Made During Grant Period

Goal I: Increase accurate and timely documentation of UNHS information by hospitals and free-standing birthing centers.

Objective 1: All birthing hospitals and free-standing birthing centers will enter complete and accurate UNHS information into IPHIS and submit the paper report forms to ODH within ten days of the infant's hospital discharge.

Objective 2: ODH will obtain hearing screening results and primary care physician information for missed or transferred infants, as well as infants who are residents of Ohio, who were born elsewhere.

Progress: IHP staff audiologists review and monitor hearing screening data via the IPHIS or electronic birth certificate data system, as well as, through the HI*TRACK data platform. The two databases provide up to date information on hearing screening results, limited maternal demographic data, transfer information, missed infants and other useful information.

Data is reviewed quarterly and hospital technical assistance is provided for any noncompliance issues or for clarification of information. Some of the challenges with the reporting of hearing screening data in IPHIS are the time delay from the time of screening to the time of data entry. In some situations, time delays have impacted the follow up post discharge.

Staff audiologists continue to provide specific technical assistance to ensure that the data is submitted accurately and within appropriate timelines. Hospitals are educated about the importance of their role in submitting correct data and how data could impact the follow up coordination after screening. Hospitals that do not meet the reporting requirements are monitored closely to ensure data is entered and imported into Hi*Track.

Additionally, the follow up coordinators at the Regional Infant Hearing Programs are informed of babies that need audiological follow up, especially if there are delays in reporting by hospitals. Protocols have been established with border states to provide an exchange of information regarding a baby's hearing screening and/or follow up results. The IHP routinely receives information from border states for Ohio residents and also sends hearing screening results to the respective state for out of state residents.

Goal II: Increase the number of babies who receive audiology evaluations due to a non-pass hearing screening result, a missed hearing screening, or an out of hospital birth.

Objective 1: Hospital personnel will communicate non-pass hearing screening results and related information to parents/caregivers in a culturally competent manner while emphasizing the need to schedule a follow-up audiology evaluation.

Objective 2: The Regional Infant Hearing programs will communicate with the families and primary care physicians for all known infants with a non-pass UNHS and without a follow-up audiology evaluation.

Objective 3: ODH will facilitate improved communication between pediatric audiologists, families and hospitals by maintaining and disseminating resource lists.

Progress: The lost to follow up rate in Ohio has decreased. The NICHQ learning collaborative provided a good framework for stakeholder groups and NICHQ state team members to develop creative ways to assist with reducing the number of babies that are lost to follow and/or lost to documentation.

The Parent Focus Group created a unique, non directive educational component for hearing screeners. The package consisted of 4 parent-written letters, an introduction letter, the Hands and Voices Loss and Found video along with an online survey. Additionally, a scripted message was provided to hospital screeners with a follow up maternal questionnaire. The focus of this PDSA cycle was to ensure that screeners provided specific information while counseling families about hearing screening results and follow up timelines. Both of these PDSA cycles were geared towards hospital hearing screeners; however the impact of the information and education resulted in improved education of both screeners and parents and impacted follow up rates positively.

The Regional Infant Hearing Programs have many responsibilities in terms of tracking and following referred babies. Customized letters and protocols have been established to ensure that physicians are appropriately referring babies for an audiology follow up.

There were several PDSA cycles that were specific to pediatric audiologists. One example was ensuring the follow up evaluations are documented on the standard ODH paper form and reported to the state EHDI program. Ohio would like to streamline data reporting from paper reporting to electronic reporting via the web version of Hi*Track. The upcoming funding opportunities would allow for the IHP to begin piloting this process with a few of the Children's Hospital Diagnostic Centers. Other updates included reviewing data reported by facilities for follow up and then providing specific guidance, education and assistance in understanding the importance of reporting follow up information and making appropriate referrals to RIHP and Part C- EI.

Goal III: Increase the enrollment of infants and toddlers diagnosed with a permanent hearing loss into early intervention services.

Objective 1: The Regional Infant Hearing program will provide specialized Early Intervention services for children with permanent hearing loss and their families.

Progress: A unique PDSA was created to review enrollment dates from two separate databases to ensure that EI enrollment dates were consistent with the IFSP dates. This cycle started with one RIHP and each month another RIHP was added. This process outlined discrepancies that existed with Early Intervention enrollment dates between data base systems and allowed for verification of the date of enrollment to be consistent among two data systems for the child. Some of the information regarding refused enrollment is not captured appropriately and the IHP would like to begin looking into the percentages of enrollment versus non enrollment in the state EI and RIHP programs and review potential reasons for refusals. This process will be utilized to develop additional PDSA's to determine potentials reasons for parent/family refusals as this impacts the percentage of enrollment in our program.

Goal IV: The IHP will consult with the UNHS Advisory Subcommittee and other stakeholder groups to obtain input, recommendations, and feedback on newborn hearing screening, diagnosis, and intervention.

Objective 1: ODH will share program information and data with the UNHS Advisory Subcommittee every quarter of the grant year.

Objective 2: ODH will share program information and data with the NICHQ Learning Collaborative.

Progress: The Infant Hearing Screening Subcommittee met quarterly during this grant cycle as regularly scheduled with the exception of two late winter meeting cancelled due to inclement weather. At each meeting a general NICHQ state team update was provided, specific issues were discussed, and workgroup time was a standing agenda item. Workgroup members provided updates at the end of each meeting and were in contact through email and conference calls between meetings. The work groups assisted the IHP program by spreading quality improvement work among a varied group of stakeholders. The Legislative Report and CDC data were shared with the members of the subcommittee.

Work Plan

Goal:

By March 31, 2017, the Ohio Department of Health, Infant Hearing Program will reduce Lost to Follow-up and Lost to Documentation from 37% to 22% by focusing on the timely transition of infants (1) from hearing screening referral to diagnostic audiology evaluation and (2) from diagnosis of permanent hearing loss to enrollment in early intervention while monitoring 1-3-6 EHDI milestones.

Aim Statement 1: By March 31, 2015, the number of infants who receive an audiology evaluation following a non-pass UNHS result will increase by 5%.

Objective 1.1: Birthing facilities identified as having more than 25% of infants with non-pass UNHS results that are lost to follow-up will be decreased by 5%.

Activities	**Start Date**	**Completion Date (Est.)**	**Person(s) Responsible**	**Evaluation Methods**	**Outcome Measures**
1. At least 3 hospital partners, meeting the above criteria, will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	3 hospital partners engaged
2. At least 3 parent partners with children who did not pass their UNHS and followed through on having their child evaluated by an audiologist will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	3 parent partners engaged
3. Develop non-pass scripted communication for delivering hearing screening results and a written maternal survey to assess understanding of scripted message.	June 1, 2014	July 31, 2014	IHP Staff, Hospital Partners, Parent Partners	Tool usefulness will be evaluated/modified until product is final	Tool accepted as useful
4. Screeners will use a scripted message when communicating non-pass	July 1, 2014	March 31, 2015	Hospital Partners, IHP	a)Baseline lost to f/u calculated for	a)100% of families with infants who

hearing screening results to parents/guardians/caregivers and following the delivery of the message; assess knowledge of the information received through the use of a questionnaire. (PDSA)			Staff	participating hospitals from existing data in HT b)Number of families receiving questionnaire documented on a monthly basis by hospital and sent to ODH c) Number of infants with audiology evaluations documented in HT database whose families received the questionnaire is calculated on a monthly basis	referred on their hearing screening will receive scripted message and questionnaire b)ODH receives 100% of questionnaires sent by hospitals c) Lost-to- follow-up rate is compared with baseline to determine trends.
5. Written materials/brochures describing payment options developed	Aug. 1, 2014	Sept. 30, 2014	IHP Staff	Tool usefulness will be evaluated/modified until product is final	Tool accepted as useful
6. Hospital personnel will provide parents/guardians/caregivers of infants who do not pass their UNHS with payment resources for diagnostic audiology follow-up. (PDSA)	Oct. 1, 2014	March 31, 2017	IHP Staff	Calculate the number of families who received payment resource information information and followed through with an appointment based on a documented hearing evaluation	100% of families with infants not passing their UNHS are offered the resource guide for diagnostic audiology payment options.

7. Hospital personnel will schedule a follow-up audiology appointment with parental consent before hospital discharge. (PDSA)	August 1, 2014	March 31, 2017	IHP Staff, Hospital Partners	The percentage of families with scheduled audiology appointments prior to hospital discharge who keep the appointment, documented by receipt of the Audiology Follow-Up report at ODH will be calculated.	100% of infants with non-pass screening results will have an appointment for a follow-up audiology appointment scheduled before hospital discharge
8. Written communication for relaying non-pass hearing screening results and next steps for follow-up will be translated into Spanish. (PDSA)	Jan. 1, 2014	TBD	IHP Staff, Hospital Partners	The percentage of families who receive the written communication for next steps in Spanish and have a documented audiology evaluation for their newborn will be calculated.	100% of families whose first language is Spanish will receive the translated written information

Objective 1.2: The number of audiology diagnostic reports received by ODH within 7 days of the evaluation date will increase by 10%.

Activities	**Start Date**	**Completion Date (Est.)**	**Person(s) Responsible**	**Evaluation Methods**	**Outcome Measures**
1. At least 2 Regional Infant Hearing Programs will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	2 Regional Infant Hearing Programs engaged
2. At least 2 Audiology Facilities will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	2 Audiology Facilities will be engaged

3. Regional Infant Hearing Program (RIHP) data specialists will identify non-reporting audiologists through follow up phone calls with parents/guardians/caregivers and request documentation of the results on the standardized state report form. (PDSA)	April 1, 2014	TBD	RIHP Staff, IHP Staff	The percentage of reports received compared to the total number of reports requested will be calculated.	Decreased number of discontinued records in HI Track database due to lost to documentation
4. A selected audiology facility will participate in increasing the number of follow-up forms sent to the state EHDI program by incorporating strategies including placing reminder cards and Audiology Follow-up Forms in the audiology suites. (PDSA)	June 1, 2014	TBD	Audiology Partners, IHP Staff	a)Establish baseline for number of reports sent to ODH b) Calculate the percentage of reports sent from the total number of evaluations for infants who referred on their UNHS following each strategy	Increases in the number of audiology reports sent to ODH increases the number of completed evaluations tracked in the HI Track data base

Objective 1.3: The number of families that keep scheduled audiology diagnostic appointments for infants not passing their hospital hearing screening will increase by 5%.					
Activities	**Start Date**	**Completion Date (Est.)**	**Person(s) Responsible**	**Evaluation Methods**	**Outcome Measures**
1. At least 2 Audiology Facilities will continue to be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	2 Audiology Facilities engaged
2. At least 3 family partners will be engaged to assist with developing materials	Aug. 1, 2014	Sept. 30, 2014	IHP Staff LTF/LTD Team	N/A	3 family partners engaged
3. Selected audiology facilities will document missed appointments due to no shows and rescheduling of appointments on the Audiology Follow-up Report form and submit this information to ODH within 7 days of the missed appointment. (PDSA)	June 1, 2014	March 31, 2017	Audiology Partners/IHP Staff/RIHP Partners	The percentage of rescheduled appointments tracked to completion will be calculated	Increased number of completed evaluations in the HI Track database
4. Selected audiology facilities will provide families with written and/or verbal instructions on how to prepare their infant for a diagnostic evaluation (PDSA)	Oct. 1, 2014	TBD	Audiology Partners/ IHP Staff	The percentage of families who receive the information, the method the information is received and the success rate of the evaluation will be calculated based on the number of completed evaluations.	Increased number of completed evaluations in the HI Track database
5. Selected audiology facilities will provide appointment reminders to	Jan. 1, 2015	TBD	Audiology Partners/IHP	The number of families who receive	Increased percentage of completed evaluations

families via voice mail and/or postal service including the date and time of the appointment. (PDSA)			Staff	appointment reminders, the method by which the reminder is received and the number of completed evaluations will be calculated and compared to the number of no shows and cancelled appointments.	
Aim Statement 2: By March 31, 2015, the number of infants and toddlers receiving early intervention services due to a documented permanent hearing loss will increase by 15%.					
Objective 2.1: The documentation of infants and toddlers receiving non Part C services will increase by 10%.					
Activities	**Start Date**	**Completion Date (Est.)**	**Person(s) Responsible**	**Evaluation Methods**	**Outcome Measures**
1. At least 3 Regional Infant Hearing Programs will be engaged	Aug. 1, 2014	Oct. 1, 2014	IHP Staff LTF/LTD Team	N/A	3 Regional Infant Hearing Programs engaged
2. Develop a Parent Survey for families refusing RIHP EI services listing Non Part C alternatives for Early Intervention	Oct. 15, 2014	Dec. 15, 2014	RIHP Partners/IHP Staff	Tool usefulness evaluated/modified based on RIHP knowledge	Tool usefulness accepted by RIHP Partners
3. Regional Infant Hearing Program personnel will survey families who elect not to enroll their child in Help Me Grow Part C services to track reasons for their decisions. (PDSA)	Jan. 1, 2015	June 30, 2015	RIHP Partners	Survey responses documented and stored in Excel to calculate modal frequency	Identifying non-Part C services improves data collection

4. Regional Infant Hearing Program personnel will document parent/guardian/caregiver election of non-part C services in HI Track. (PDSA)			RIHP Partners	User-defined Hi Track report to verify data entry and calculate percent of infants with diagnosed permanent hearing loss who receive either Part C or Non-Part C services	Data collection of non-Part C services added to HI Track decreases the percent of infants lost between diagnosis and intervention leading to increased accuracy of CDC report
Objective 2.2 100% of infants and toddlers receiving services through the Regional Infant Hearing Program (RIHP) will have an IFSP documenting RIHP services in the Early Track database.					
Activities	**Start Date**	**Completion Date (Est.)**	**Person(s) Responsible**	**Evaluation Methods**	**Outcome Measures**
1. At least 3 Help Me Grow Service Coordinators will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	3 Help Me Grow Service Coordinators engaged
2. At least 1 Help Me Grow researcher will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	1 Help Me Grow Researcher engaged
3. Chart audits for infants and toddlers in selected regions of the state will be used to identify data entry errors in the Part C Early Track data base across 7 fields. (PDSA)	July 1, 2014	Dec. 31, 2014	Help Me Grow Partners/IHP Staff	Analyze data entry errors from reported information by Help Me Grow Service Coordinators	Identify areas of the state where data entry for Regional Infant Hearing Program EI services are not input using standardized fields
4. Action plans to ensure unified data entry for infants and toddlers enrolled in the regional Infant Hearing Program will be developed and implemented	Jan. 1, 2015	TBD	IHP Staff/ RIHP Staff	Data report from Early Track matched to HI Track data report of infants and toddlers	Accurate and matching numbers of infants and toddlers receiving EI services are housed in

based on findings. (PDSA)				enrolled in Part C services will be matched for accuracy	the HI Track data base and the Early Track data base.

Objective 2.3 The enrollment of infants and toddlers with a diagnosed permanent hearing loss in the Regional Infant Hearing Program will increase by 10%.

Activities	Start Date	Completion Date (Est.)	Person(s) Responsible	Evaluation Methods	Outcome Measures
1. At least 3 families with children who participated in the Regional Infant Hearing Program will be engaged.	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	3 families engaged
2. At least 3 Regional Infant Hearing Programs will be engaged	Apr. 1, 2014	June 1, 2014	IHP Staff LTF/LTD Team	N/A	3 Regional Infant Hearing Programs engaged
3. Parent letters in support of the Regional Infant Hearing Program from families who previously participated in the program are developed	June 1, 2014	July 1, 2014	Parent Partners/ RIHP Partners	Tool usefulness evaluated/modified based on input from RIHP Partners	Tool usefulness accepted by RIHP partners
4. Parent letters in support of the Regional Infant Hearing Program will be sent to families who express the need for more information about the program before making a decision as to whether or not to accept Part C services. (PDSA)	July 1, 2014	March 31, 2017	RIHP Partners	The number of letters sent and the number of parents who enroll their child in Part C services will be calculated as a percent	Increased number of infants and toddlers receiving Part C services

5. At least 3 Audiology Facilities will be engaged	May 1, 2014	June 30, 2014	IHP Staff LTF/LTD Team	N/A	3 Audiology Facilities engaged
6. Diagnosing audiologists from selected audiology facilities will provide Regional Infant Hearing Program brochures to families of infants and toddlers diagnosed with a permanent hearing loss. (PDSA)	July 1, 2014	March 31, 2017	Audiology Partners/ RIHP Partners	Increase in the percentage of audiology facilities distributing RIHP information	Parental awareness of the program leads to increased enrollment