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**Program:** Ohio Department of Health, Infant Hearing Program

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## **Introduction**

The Ohio Department of Health (ODH) Infant Hearing Program (IHP) was developed and is maintained under the authority of the Universal Newborn Hearing Screening legislation enacted in 2004 requiring all birthing hospitals and free-standing birthing facilities within the state to provide a hearing screening for each newborn before the newborn is discharged from the hospital.

The IHP follows the national Early Hearing Detection and Intervention Program (EHDI) 1-3-6 guidelines for screening, diagnosis and Early Intervention (EI) for infants with a permanent, confirmed hearing loss, reporting key indicators annually to the Centers for Disease Control and Prevention (CDC). The Program supports the recommendations of the Joint Committee on Infant Hearing recommendations for evaluation and periodic assessment.

Hospitals and birthing facilities report demographic and other birth information, including hearing screening information, electronically to the Vital Statistics Integrated Perinatal Health Information System (IPHIS) within ten business days of birth. If the results are non-pass, hospitals and birthing centers beginning December 1, 2019 must be reported to the IHP within seventy-two hours.

The IHP uses Hi\*Track, a software system designed to follow and track infant hearing screenings, referrals, evaluations and EI services. Individual demographic data on all births and initial hospital hearing screenings are extracted from the Vital Statistics Integrated Perinatal Health Information System (IPHIS) used by all hospitals to create birth records and imported into the Hi\*Track database.

Activities to identify needs for the IHP included review of finalized 2017 Hi\*Track data, surveys distributed to hospitals, audiologists and additional stakeholders regarding screening, referral, follow up and intervention services as well as recommendations from the various stakeholder groups. Consistently, the gaps identified are the need to (a) increase hearing screening amongst home births, (b) improve audiological data reporting to decrease loss to documentation, (c) improve parental support and access to resources and (d) improve relationships among and within the EHDI system.

According to 2017, Ohio's screening rate was 97.7%. A review of trend data indicated that home births continue to rise each year in Ohio. From 2014 to 2017, an increase of 10% of babies who did not receive a hearing screening were home births. This presents an opportunity to improve partnerships with midwives to maintain and/or increase the percentage of babies screened in Ohio. In 2017, Ohio also experienced an increase in missed/other reasons for not screening due to birth hospital reporting concerns regarding validity of screening results. This resulted in an increase from 2.5% in 2016 data to 14.4% in 2017 data.

Hearing evaluations are reported electronically through the Hi\*Track web submission link. Electronic reporting reduces the time period between appointments and reporting and encourages audiologists to submit notes and upcoming scheduled hearing evaluation appointments that assist with case management and reduction of lost to documentation. The

electronic submission of evaluations also allows the IHP to monitor audiologists' adherence to protocols and reduce the amount of time to refer babies to Early Intervention (EI) services.

Responsibility and funding for the Ohio Part C EI program was transitioned from the Ohio Department of Health to the Ohio Department of Developmental Disabilities (DODD) in July 2016. In 2017, the IHP relied upon Central Coordination to contact families to enroll in EI services. Since 2018, the IHP has contracted with the Ohio Coalition for the Education of Children with Disabilities (OCECD) to provide family support and resources to encourage families to schedule hearing evaluations as well as enroll in EI services.

EI plans and services for infants and toddlers with a permanent hearing loss continue to be documented in Early Track. An Interagency Agreement between ODH and DODD is in place to ensure IHP staff's continued access to the Early Track database that houses EI data. The IHP staff enter the EI data in Hi\*Track to ensure accurate data reporting for all of the EHDI guidelines.

The IHP will continue to utilize the IPHIS data and the Hi\*Track database to monitor hospital screening, infants lost to follow-up, and reporting. The hospitals receive regular reports advising them of missing or incomplete records and a public health audiologist tracks requested corrective action. The audiologist will continue to monitor hospitals including tracking for scheduling evaluation for infants with a failed hearing screening.

The IHP will continue its initiative to reach out to physicians identified as the primary care provider in the birth record to remind them that the infant needs follow-up and may need referrals for evaluation, specialty care services, and genetics, or that the infant has an appointment and they should obtain outcomes of the evaluation. Within the next grant year, the IHP will also be exploring further outreach to primary care providers, specialty medical providers, and EI specialists through learning opportunities to increase awareness of and encourage development of family centered care coordination plans. Outreach includes further collaboration with the Ohio Chapter of American Academy of Pediatrics and the state of Ohio Chapter Champion to participate in the learning community. Currently there is representation from AAP on the Universal Newborn Hearing Screening Subcommittee.

The IHP collaborated closely with members of the pediatric audiology community during this last year to participate in training for the recommended COACH protocols for comprehensive follow-up examinations of infants that fail their hospital screening as well as assessing reasons for the increase in undetermined hearing evaluation results.

In 2017, a total of 261 cases of permanent hearing loss were reported. The IHP will explore the impact of earlier and more frequent outreach and supportive efforts of OCECD in reaching out to these families and successfully linking them to EI services in a timely manner as well as re-referring families for services who are unable to contact because they are unresponsive to phone calls from the Part C service coordinators. Families who have been unresponsive to phone calls within the seven-day timeframe will be re-referred for Part C services by IHP.

Data collection and monitoring for timely screening, diagnosis, and linkages to EI services for all aspects of the EDHI 1-3-6- program will continue to be collected within Hi\*Track and Early Track and reported annually to CDC. The public health researcher assigned to the IHP will continue monitoring and analyzing data for current surveillance needs on bi-weekly, monthly and quarterly schedules and will support this program with additional data collection and specific reporting requirements in order to measure impact for this grant or to test incremental changes utilizing a QI model.

## Needs Assessment

The US Census Bureau estimates the state of Ohio has a population of 11.6 million as of July, 2018. The population of Ohio is about 81% white and 13% black. About 2.5% of the population are Asian and another 2.3% identify themselves as multi-racial. About 3.9% of Ohioans identify themselves as Hispanic or Latino (any race). (From the US Census Bureau at <https://www.census.gov/quickfacts/OH.>)

The state has a land area of 40,860 miles and is a combination of urban, suburban, and rural that make up eighty-eight counties. Ohio has a large number of rural counties scattered throughout the state. Those rural counties located in a broad swath along the eastern and southern borders of Ohio, approximately 1/3 of the State's geographic area, are a part of Appalachia and share the unique and well-documented challenges of Appalachia in general.

Several of the urban and suburban areas encompassing the large cities of Columbus and Cincinnati, are growing rapidly while those of the major cities of Cleveland, Akron and Dayton, are continuing to slowly lose residents. The wide variety of geographic areas and the demographics pose unique challenges in insuring appropriate supportive resources and high-quality services are consistently available throughout the State for all families of infants and toddlers who are deaf or hard of hearing.

The state also has a significant Amish population in some rural areas. They too face challenges regarding transportation and payment for services and can be difficult to 'connect with' from the perspective of modern medical care and intervention services because of their lifestyle choices. Although some may allow their children to be screened, most families choose not to seek diagnostic confirmation of a failed hearing screening nor to enroll in EI services.

In 2017, the annual income of Ohio residents was \$52,407. There was an increase in 2018 to 13.9% of persons in poverty according to the July 2018 census data as well as an increase 7.7% of persons without medical insurance in which 4.5% are children under the age of eighteen who do not have health insurance. In addition to income factors, other social and economic disparities impact the health of Ohio children and families such as Ohio's addiction crisis has contributed to the increase of children in foster care.

With the exception of the Census population, the broad picture of Ohio's families and children's health concerns are contained within the *Ohio 2019 State Health Assessment*, <https://odh.ohio.gov/wps/portal/gov/odh/explore-data-and-stats/interactive-applications/2019-online-state-health-assessment>.

There were 138,704 births in Ohio in 2017 and more than 97 percent of the infants were screened prior to discharge. Ohio has seen a decline in the timely screening of infants before one month of age since 2011 with 99% of infants screened before one month of age. This may be attributed to the 10% increase of homebirths since 2014 to 2017. In 2017, 97.72% infants were screened prior to one month of age

Hospital screeners and staff have a crucial role in educating the parents about the screening process, the screening results, and the next steps following the hearing screening. Screeners remind, coach and engage parents about the follow up testing and the time frame for follow up if the baby does not pass the second screening using culturally competent counseling techniques. Birthing facility and hospital staff are required to complete annual training provided by the IHP required training yearly and receive training materials to assist with having a well scripted message to share with parents. Birthing facility and hospital staff also provide

scheduling assistance to families to ensure families take the appropriate step for their infants' hearing.

The most recent data for the IHP on infants who failed hearing screenings and were evaluated or lost to follow-up confirm the broader picture of population characteristics and social disparities outlined in the *Ohio 2019 State Health Assessment*. In 2017, Ohio experienced an increase in the percentage of referrals from the newborn hearing screening (2.9% to 3.1%). This increase may be attributed to the increase in increase of low birth weight (8.7%) and premature birth weight (10.4%) that also occurred for babies born in 2017.

The IHP successfully tracks about 70% of infants identified with a failed hospital hearing screening to confirmation of either normal hearing or diagnosis of a permanent hearing loss. Quality assurance initiatives confirm the message the screener provides must be carefully crafted to ensure the parent takes the hearing screening results seriously and is motivated to follow through with a diagnostic appointment. There are barriers to making and keeping appointments including perceived accommodation of facility when parent makes the appointment, ease in making an appointment, convenient times for appointments, reliable transportation, proximity of facility, adequate preparation for appointment by family, and adequate time set aside for evaluation to be completed in one visit. Anecdotal information indicates the cost of evaluations is a barrier for some families as well. The staff conducting the evaluation must be skilled in working with a pediatric population, adhere to recommended evaluation guidelines rather than doing yet another screening and then rescheduling the family for a diagnostic work-up when that screening fails, and empathic in communicating results and next steps to parents. Our focus has been on reducing those barriers at which the completion of a diagnostic appointment and evaluation can break down so as to prevent the family from getting a definitive diagnosis.

The IHP provides follow up coordination for tracking and surveillance of infants that need hearing evaluations after non-pass hearing screening results to identify hearing loss as early as possible. For 2017 births, 3.1% of infants did not pass their UNHS. Of those infants who received diagnostic hearing evaluations, 59.4% were completed by 3 months of age. In 2017, 69.8% of infants who did not pass their UNHS before discharge received a diagnostic hearing evaluation. According to 2017 birth data, Ohio's data is lower than the Healthy People 2020 objective that identifies 72.6% as the target for infants with non-pass screening results to receive a diagnostic evaluation. The 2017 data indicates more targeted efforts are needed to make improvements in this objective in order to meet the national target as well as the HRSA target of 85%.

According to 2017 data, mothers who are less than twenty years old during birth are almost 3% more likely to have infants who will be loss to follow up than mothers who are twenty years old and above during birth. In addition to age, mothers who are black are almost 4% more likely to have infants who will be loss to follow up as compared to white (2%) and other (1%). Infants of mothers who are unmarried during the time of birth are 11% more likely to be loss to follow up. Infants of mothers who have Medicaid are more than 12% more likely to be loss to follow up and infants of mothers who are receive WIC are 5% more likely to be loss to follow up. Lastly, infants of mothers who have a high school education or less than high school education are 5% more likely to be loss to follow up.

A needs assessment was conducted in 2018 to identify areas of improvement as they related to increasing the percentage of infants with non-pass hearing screening who receive timely diagnostic hearing evaluations. The gaps identified through the 2018 Audiology Survey included decreasing the reporting diagnostic hearing evaluations, providing materials to parents

and caregivers and providing materials to audiologists to reduce the number of evaluations needed in order for families to have a confirmed diagnosis in a timely manner. As a result of the 2018 Audiology Survey, the IHP submitted final language for OAC 3701-40-08 rules that include a requirement for diagnosing audiologists in Ohio to provide IHP-approved educational materials to families as well as participating in required yearly training offered by IHP.

During 2018, audiology surveys also were used to assess the following: diagnostic testing equipment, the process of notifying a parent of hearing loss, educational materials provided to parents, the ability to share information about communication modalities in an unbiased manner, care coordination efforts, discussion with parents about Early Intervention and the subsequent referral to Early Intervention. Data was compared between the 2017 survey and the 2018 survey to identify changes in these practices. Facilities scoring low in any of these areas received a site visit from the ODH with tools and resources to help overcome barriers. Progress was measured through QI activities and improvement was noted.

In addition to conducting the needs assessment survey, data reported to the IHP were analyzed to determine reasons why the results of many diagnostic evaluations were reported as “undetermined” in an effort to reduce the frequency of these outcomes. A review of the data indicated families of infants whose first evaluation leads to inconclusive results often do not schedule additional appointments to complete testing, and those that do schedule, may not show for the next appointment. This leads to an increase in loss to follow-up rates and the potential for a late diagnosis of hearing loss. By exploring reasons for these outcomes, technical assistance was provided to audiologists to reduce inconclusive results and increase audiologists’ understanding for complete testing and reporting.

After families receive a diagnosis of a permanent hearing loss the IHP successfully links about 52% of families with EI providers. Attempts are made numerous times to encourage the remaining 21% of families to consider enrollment in EI. The remaining percentage of families refuse EI services or families are no longer Ohio residents. Again, there are numerous points where the infant and family may be lost to follow-up for EI. These barriers include the emotional impact of the diagnosis on the family and their ability at that time to work through their grief and denial, the skill of the professional in helping the family understand the long term importance of EI for the infant’s social-emotional development and making the referral for them, ease of access and convenience of services, the families’ perception of the value of EI and government-supported programs for EI, the need for yet another ‘evaluation’ and development of a care plan by the EI provider, fear of loss of control to ‘experts’, and the difficulties of care coordination. There are numerous points at which the transition from diagnosis to enrollment and provision of EI services can be improved to ensure the family is quickly enrolled in appropriate EI.

According to the 2017 data, out of the 261 infants diagnosed with permanent hearing loss, 125 infants were loss to EI enrollment. By looking at 2017 data more closely to determine areas of need and disparities, there are disparities among mothers’ characteristics of infants who are loss to follow up for EI enrollment for age, race, ethnicity, marital status, insurance and education. According to 2017 data, mothers who are thirty-five years or older old during birth are almost 5% more likely to have infants who will be loss to follow up for EI enrollment than mothers who are less than thirty-five years old during birth. In addition to age, mothers who are black are almost 4% more likely to have infants who will be loss to follow up for EI enrollment as compared to white and other races. Infants of mothers who are unmarried during the time of birth are 3% more likely to be loss to follow up for EI enrollment. Infants of mothers who have

Medicaid are more than 6% more likely to be loss to follow up for EI enrollment. Lastly, infants of mothers who have some college education are 5% more likely to be loss to follow up to EI enrollment.

Overall, 2017 data for Ohio provides consistent disparities for loss to follow up for diagnostic evaluations and EI enrollment are black mothers, unmarried mothers and mothers on Medicaid. Through this assessment, the IHP has determined a need to continue to focus on reducing these disparities by reaching out to programs who specifically target these populations such as Ohio Medicaid, Home Visiting as well as utilize the Office of Health Equity housed within ODH.

The 2017 data also highlighted areas of success from the previous 2016 data which included an increase in the percentage of infants identified with permanent hearing loss, an increase in the percentage of infants who were diagnosed with permanent hearing loss before three months of age as well as an increase of infants with permanent hearing loss who enrolled in EI service. Although these are successes, additional target areas have been identified such as the increase in the percentage of newborns who missed their hearing screenings, a decrease in the percentage of infants enrolling in EI by six months of age and an increase in the percentage of parents and guardians who were unable to be contacted for EI enrollment.

## **Methodology**

The IHP recognizes that EHDI is a complex program that truly relies upon the systems approach to care in order to meet desired goals and outcomes. The IHP proposes to work with diverse work groups of stakeholders statewide and local partners to reduce gaps and improve the EHDI system for our families is necessary. The IHP proposes to lead efforts to engage and coordinate all stakeholders in the state to meet each of the goals of EHDI to ensure that all newborns are screened before one month of age, infants with non-pass screening results are diagnosed by three months of age, infants diagnosed with hearing loss are enrolled in EI before six months of age, reduce loss to follow up for documentation and loss to follow up through purposeful stakeholder and professional engagement.

The IHP proposes to maintain or increase by 1% from baseline to achieve at least 95% screening rate for the number of infants who receive a completed hearing screen no later than one month of age. According to 2017 data, 96.3% of Ohio births were screened before one month of age. The IHP will lead coordinated infrastructure efforts to engage and coordinate stakeholders in EHDI to ensure that all newborns are screened by one month of age. An action work group will be established under the Universal Newborn Hearing Screening Advisory Subcommittee with the assistance of various stakeholders such as parents, hospital screeners, screening contractors, primary care physicians, data clerks, midwives and doulas to assist in the recommendation, review and implementation of interventions to meet screening objectives. Hospitals and birthing centers will continue to receive support and technical assistance to ensure that all babies born will receive hearing screenings when possible by the Public Health Audiologist. This intervention is ongoing and is evaluated on a quarterly basis through report cards.

In addition to technical assistance and support from IHP, parents and guardians will be provided culturally appropriate materials regarding the importance of hearing screenings before one month of age. The number of these materials provided will be evaluated to maintain or increase the number of babies who receive hearing screenings before one month of age.

Due to the steady increase of home births in Ohio, the IHP will also propose representation from Midwives as a required member of the Universal Newborn Hearing Screening Advisory Subcommittee. This will allow representation from a diverse stakeholder group that has not been included previously and may increase the percentage of home births babies to receive a completed hearing screening before one month of age.

Lastly under this objective, the IHP will explore quarterly recommendations for infrastructure improvements from the Universal Newborn Hearing Screening Subcommittee. Each quarter, members from the Subcommittee provide recommendations for improvements to IHP. The IHP will utilize QI methods to test the highest-ranking recommendation and determine if the recommendation is impactful and sustainable. The QI testing will be implemented through the action work group established to impact the screening of newborns.

The IHP proposes to increase by 10% from baseline the number of infants that completed a diagnostic audiological evaluation by no later than 3 months of age. According to 2017 data, 59.4% of referrals were diagnosed by 3 months of age; however, 69.8% regardless of age received a completed diagnostic audiological evaluation. Activities proposed by IHP to impact this objective are to lead coordinated infrastructure efforts to engage and coordinate stakeholders in the EHDI system to ensure that infants are diagnosed by three months of age, reduce loss to follow-up rates, reduce loss to documentation rates, implement quality improvement method strategies and work with the EHDI National Technical Resource Center to implement these activities. An action work group will be established under the Universal Newborn Hearing Screening Advisory Subcommittee with the assistance of various stakeholders such as parents, Ohio Coalition for the Education of Children with Disabilities (OCECD), hospital screeners, screening contractors, Home Visitors, Community Health Workers, CMH public health nurses, LEND students, Free Clinics, primary care physicians, audiologists, and ENTs to assist in the recommendation, review and implementation of interventions to meet diagnostic hearing evaluation objectives.

The training of audiologists on the COACH protocols has been successful in identifying an additional 1.1% of babies with permanent hearing loss in 2017. The IHP proposes to explore additional steps to improve performance among audiologists using audiology facility performance reports. These reports will assist in increasing the percentage of audiology facilities with improved performance reporting.

The IHP will continue to contract with the Ohio Coalition for the Education of Children with Disabilities (OCECD). This family-based agency will be responsible to contact families whose children did not pass the hearing screening prior to discharge and provide support and resources for families to encourage the next step of scheduling and attending the diagnostic appointment. OCECD will track the outcome of each phone call made to these families. OCECD is required to make at least two phone call attempts within seven calendar days to each family whose infant did not pass the hearing screening prior to discharge. The IHP will track the number of families contacted as well as the number of diagnostic appointments scheduled for families to achieve the outcome of increased percentage of infants diagnosed by three months of age.

The IHP will explore quarterly recommendations for infrastructure improvements from the Universal Newborn Hearing Screening Subcommittee. Each quarter, members from the Subcommittee provide recommendations for improvements to IHP. The IHP will utilize QI methods to test the highest-ranking recommendation and determine if the recommendation is

impactful and sustainable. The QI testing will be implemented through the action work group established to impact diagnostic hearing evaluations.

In order to reduce loss to follow-up, the IHP will explore revising the COACH and ENT guidance to reflect best practices and recommendations for middle ear fluid management. An estimated 8% of Ohio's 25% loss to follow up can be attributed to infants who do not return for a diagnostic hearing evaluation following the medical treatment of middle ear fluid. Other states have explored the use of specific testing by audiologists prior to referral for ENT.

In addition to parents or guardians not scheduling appointments, Ohio experienced an increase in parents who were unable to contact due to incorrect or outdated contact information. As a result, the IHP will begin to contact families initially by four weeks of birth and explore the ability of capturing email addresses from parents so any additional contact could also be provided through email as opposed to telephone and mailings.

In order to reduce loss to documentation, the IHP will explore new data sharing with the Birth Defects Registry as well as Children with Medical Handicaps (CMH) to identify infants who have been diagnosed with permanent hearing loss and reported to other ODH programs. An initial test to determine the viability of this approach was completed and it was successful in determining that both programs had additional hearing diagnostic information that was not available in the IHP.

Primary care physicians listed at the time of birth will also be contacted at various points before the six month well child visit to encourage diagnostic follow up as well as reporting diagnostic follow up to the IHP in the form of fax back letters. This has been a successful QI project that is sustainable for the IHP and continues to increase the number of infants with confirmed diagnoses.

The IHP will also provide training and technical assistance to audiologists to increase the number of evaluations submitted to IHP. Targeted technical assistance will be provided to audiologists who were responsible for completing the evaluations that were identified as possible loss to documentation. In addition, in December 2019, the Ohio Administrative Code will be expanded to include the submission of diagnostic hearing evaluations to IHP for all newborns, infants and toddlers up to the age of three who had non-pass hearing screening results as well as results in which the type and/or degree of hearing has changed from the previous appointment.

It was identified through onsite trainings that audiologists were not consistently reporting evaluations to the IHP when required. In order to improve technical assistance to audiologists, a variety of tools will be tested utilizing QI methods to determine the most effective and impactful approach to provide targeted technical assistance to audiologists. The projected outcome for this approach will be an increase of infants meeting the three-month timeline of receiving a complete diagnostic audiological evaluation. Such approaches to technical assistance will be reviewed through various resources such as the EHDI National Technical Resource Center as well as the UNHS Advisory Subcommittee action work group that is comprised of various stakeholders.

The IHP proposes to increase by fifteen percent from baseline the number of infants identified to be DHH that are enrolled in EI services no later than six months of age through a variety of activities and interventions. In 2017, the IHP EI enrollment before six months of age was thirty-two percent. Activities proposed by IHP to impact this objective are to lead coordinated infrastructure efforts to engage and coordinate stakeholders in the EHDI system to ensure that infants are enrolled in EI services by six months age, to implement a data sharing agreement with private EI providers to share data more consistently, provide training and talking points to audiologists regarding the benefits of EI services, test the direct referral of parents and

guardians for EI services during the diagnostic appointment, explore providing Ski Hi training to EI providers, quality improvement method strategies and work with the EHDI National Technical Resource Center to implement these activities. An action work group will be established under the Universal Newborn Hearing Screening Advisory Subcommittee with the assistance of various stakeholders such as parents, Ohio Coalition for the Education of Children with Disabilities (OCECD), Home Visitors, Community Health Workers, CMH public health nurses, LEND students, service coordinators, central coordination staff, Department of Developmental Disabilities, audiologists, children's hospitals, ENTs to assist in the recommendation, review and implementation of interventions to meet EI enrollment objectives.

The IHP will continue to contract with the Ohio Coalition for the Education of Children with Disabilities (OCECD). This family-based agency will be responsible to contact families whose children have been diagnosed with hearing loss and provide support and resources for families to encourage the enrollment in EI services. OCECD will track the outcome of each phone call made to these families. OCECD is required to make at least two phone call attempts within seven calendar days to each family whose children have been diagnosed with hearing loss from birth up to age three years old. The IHP will track the number of families contacted as well as the number of families who indicate interest in EI enrollment to increase the percentage of infants enrolled by six months of age. In addition to supporting the families with materials guidance, parents and guardians will also receive culturally appropriate materials that will assist in the EI process. OCECD will also capture enrollment information in private EI services from parents and guardians.

The IHP has identified three key children's hospitals that may be willing to share their private EI enrollment data. These hospitals are Nationwide Children's Hospital, Cincinnati Children's Hospital Medical Center and University Hospitals Rainbow Babies. The IHP will explore the possibility of capturing enrollment data for infants and toddlers identified with hearing loss in order to increase the percentage of infants enrolled in EI services by six months of age.

In addition to data sharing, the IHP proposes to provide training to the Part C EI providers utilizing the Ski Hi training. Through anecdotal evidence, parents and health care providers have expressed concern that a standard curriculum should be utilized in Part C EI services for infants and toddlers diagnosed with hearing loss. The IHP proposes to provide this training for the Part C EI providers that will encourage current EI providers to be trainers of the curriculum as well as train other service providers who have not been trained before on Ski Hi. The IHP intends to utilize this standard training and approach as a discussion point with health care providers and parents and guardians who may be hesitant to enroll in Part C EI services.

The IHP will explore quarterly recommendations for infrastructure improvements from the Universal Newborn Hearing Screening Subcommittee. Each quarter, members from the Subcommittee provide recommendations for improvements to IHP. The IHP will utilize QI methods to test the highest-ranking recommendation and determine if the recommendation is impactful and sustainable. The QI testing will be implemented through the action work group established to impact enrollment in EI services.

The IHP proposes to utilize QI methods to test a recently developed EI booklet that includes unbiased information of communication options, draft IFSP goals for families, a draft communication plan and an overall message to help parents and guardians cope with the diagnosis of hearing loss. The testing will occur to determine the most impactful location to

provide this booklet to families such as the during the diagnostic appointment, mailed following the appointment or provided by OCECD during the initial contact of parents and guardians.

The IHP also proposes to utilize QI methods to identify the most appropriate time to re-refer families for Part C EI services. The IHP reviewed 2018 data of infants referred for EI services and thirty-percent of these records revealed that parents and guardians were in process of completing a signed IFSP; however, the records were closed due to parental or guardian lack of contact within an identified time frame. The IHP proposes to explore the most appropriate time to re-refer these families for services in order to increase EI enrollment by six months of age.

The IHP proposes to increase by twenty percent from baseline the number of families enrolled in family to family support services by six months of age. During the initial year, the IHP proposes to develop the infrastructure to capture family to family support. Activities proposed by IHP to impact this objective are to explore family to family support criteria and capture enrollment to establish baseline data. The IHP will review materials from the EHDI National Technical Resource Center and the Family Leadership in Language and Learning to determine gaps in current family support. The IHP also proposes to explore multiple outreach methods to communicate the availability family support services and family support events to increase the knowledge of these events and services as well as increase participation in these events and services.

The IHP will financially support one family member to attend the annual EHDI meeting that will be located in Cincinnati, Ohio. In addition to supporting a family, the IHP will also financially support staff from OCECD to attend the annual EHDI meeting.

The IHP will continue to contract with the Ohio Coalition for the Education of Children with Disabilities (OCECD). Once a tracking protocol has been established, OCECD will track the number of families enrolled in family support in order to establish the baseline data.

The IHP proposes to increase by ten percent from baseline the number of families enrolled in DHH adult-to-family support services by nine months of age. During the initial year, the IHP proposes to develop the infrastructure to provide and capture DHH adult-to-family support. Activities proposed by IHP to impact this objective are to develop capacity for and availability of DHH adult-to-family support mentors, review materials available at EHDI National Technical Resource Center and the Family Leadership in Language and Learning regarding DHH adult-to-family support to serve as the foundation of the program. The IHP will provide the Deaf Mentors training and Snapshots training from the University of Utah to thirty DHH adults who reside in Ohio.

The IHP will continue to contract with the Ohio Coalition for the Education of Children with Disabilities (OCECD). This family-based agency will be responsible to contact families whose children have been diagnosed with hearing loss and provide support and resources for families to encourage the enrollment in EI services. OCECD will inform parents and guardians of the DHH adult-to-family support services and track willingness to participate in these services within the IHP data and case management system.

The IHP will utilize a contractor to implement the criteria established to provide DHH adult-to-family support by nine months of age as well as compensate the DHH providers for their support of Ohio's families. QI methods will be utilized to test the approach to DHH adult-to-family support to increase the percent of families who utilize this support by nine months of age.

The IHP proposes to increase by ten percent the number of health professionals and service providers trained on key aspects of the EHDI program that include knowledge of Ohio's

EHDI program, the 1-3-6 recommendations and the importance of timely screening, diagnostic, referral and EI enrollment, the need for hearing screening up to age three years old, benefits of patient/family centered medical home and family engagement of DHH child and importance of communicating accurate and unbiased information.

The IHP proposes to provide improved training opportunities and consistent outreach opportunities with state and local partners that impact the EHDI system. As an outcome of the needs assessment to determine areas of need across the EHDI system, the IHP proposes to develop and implement a communication plan that will incorporate a variety of Ohio EHDI topics that will be offered throughout the grant year. Participation in trainings, webinars, grand rounds will be collected. The IHP will also continue to collect the number of stakeholders that participate in reading the monthly newsletters, review information on the IHP website, share social media posts, etc. The IHP also proposes to continue the process of informing stakeholders about the availability of trainings and webinars that are available through the EHDI National Technical Resource Center and the Family Leadership in Language and Learning Center.

The IHP proposes to strengthen EHDI partnerships by ten percent as identified by needs assessment to reduce gaps in services and barriers to families so as to provide comprehensive wrap around services and support to all families with a DHH infant or child up to the age of three. Activities and interventions that are proposed by the IHP will be impacted by the results from the statewide EHDI system needs assessment as well as the communication plan.

The IHP proposes to work with a variety of stakeholders to develop the infrastructure and plan to collect and report hearing screening for children up to the age of the three. The stakeholders will assess the ability to collect this information as well as materials and training needed in order to collect this information uniformly. This will result in the use of an assessment tool that will be used to determine the feasibility of data collection and the targeted approach to collect this data whether from Head Starts, child care centers, Home Visiting, Physician offices, and other providers.

The IHP proposes to establish, maintain and improve partnerships for the referral, training and information sharing with various stakeholders. The IHP will disseminate an EHDI system needs assessment that will be provided to stakeholders to complete to assess the entire EHDI system that includes parent support, training needs, partnership knowledge, communication outreach needs, etc. The needs assessment will identify partnership gaps and areas of improvement for the IHP to focus on improving. Depending upon areas of need, the identification of key stakeholders and gaps will be identified.

The IHP will maintain and update the IHP website with culturally appropriate and comprehensive information regarding the IHP program. The IHP will request updates to the website when necessary and review website criteria on a quarterly basis to ensure the most accurate and appropriate information is available. The website review will ask for additional stakeholders to review new information such as the UNHS Advisory Subcommittee, OCECD, Office of Health Equity, OCECD as well as IHP staff. The IHP will also utilize QI methods to assess the sustainability of this approach to improve accessibility of information on the website.

The IHP will facilitate partnerships among families, health care professionals and service providers to understand the best strategies to engage families. The IHP will review information available through EHDI National Technical Resource Center and the Family Leadership in Language and Learning Center to identify additional strategies to engage families and assess the impact of these strategies among Ohio families within the EHDI system needs assessment and incorporate identified strategies within the communication plan.

The IHP will assess the status of coordination across early childhood programs and develop a plan to improve coordination and care services through a variety of mechanisms based on the current level of integration across programs including early childhood programs such as Part C, Home Visiting and Early Head Start. By the end of the first grant year, the IHP will establish a plan to identify future activities to overcome barriers identified by the EHDI system needs assessment results. The development of the plan will occur in partnership with stakeholders who represent Home Visiting, Part C, Head Start and Early Head Start, Ad Hoc Hearing Screening Advisory Committee, Office of Health Equity, family partners, OCECD as well as the UNHS Advisory Subcommittee.

Finally, the IHP will develop an encompassing communication plan to implement outreach and education to families through multiple communication methods as a result of the EHDI system needs assessment. The IHP with the assistance from various stakeholders, will conduct outreach and education to inform families about opportunities to be involved in different roles within the state EHDI system and collaborate with various leaders and policy makers in addressing the challenges to and providing solutions for the EHDI system.

### **Advisory Committee**

The IHP will continue to consult with the Universal Newborn Hearing Screening (UNHS) Advisory Subcommittee. This advisory oversight group, with a specific membership of 20 positions outlined by law plus “any other person the advisory committee appoints” represents key stakeholders throughout the continuum of screening at birth to diagnosis to provision of EI services and includes various hospital representatives, audiologists, and EI providers as well as adults who are deaf, representatives of the Ohio School for the Deaf, the Department of Developmental Disabilities-Part C EI, Office of Head Start, Department of Education and family members of children who are deaf or hard of hearing.

The membership of the Advisory Committee has struggled with reaching the 25% requirement for participants to be DHH adults and parents and guardians of children who are DHH. The IHP has been actively seeking additional parent partners but travel to a central location for regular meetings has been a barrier for interested parents outside of the Columbus metropolitan area and due to budgetary decreases, the IHP does not have the funding to provide stipends to parents or guardians. The advisory committee has established a newly organized group to specifically focus on membership and increasing membership from DHH adults and parents and guardians of children who are DHH.

The Subcommittee members offer an invaluable perspective on family concerns and Program plans and projects. They provide ‘hands-on’ expertise and serve as advocates within the broader community of individuals and organizations working to support the needs of families of infants and toddlers who are deaf or hard of hearing.

The Subcommittee continues to be instrumental when providing recommendations for improvement during each quarterly meeting. The Subcommittee evaluates and ranks each recommendation provided for screening, diagnostic and early intervention categories. The IHP utilizes QI methods to test the highest-ranking recommendation and determine if the recommendation is impactful and sustainable.

As described within the methodology section, the advisory committee will begin to establish action work groups comprised of advisory committee members and non-members to assist in providing recommendations, review and implementation of activities to meet the EHDI goals.

## **Work Plan**

The ongoing goals of the IHP in Ohio align with the national goals for meeting the EHDI 1-3-6 timelines through increased education and building stronger linkages with families, providers, and early intervention specialists.

The work plan defines the objectives, activities, interventions, start and end dates, evaluation methods and outcome measures. Activities included within the work plan are to lead efforts to engage and coordinate all stakeholders in the EHDI system to meet the goals of this program; to develop, document and implement plans for attaining outlined goals; and to facilitate endeavors to ensure all families and infants have optimal support for communications development.

Please see the Work Plan for details on each objective as well as each activity, timelines for the activity, responsible person or organization, proposed evaluation methods, and outcome measurements.

## **Challenges and Resolution**

There are many challenges to implementing a successful EHDI program because there are numerous points in the continuum from screening to diagnosis to enrollment in EI where a family can be lost to the EHDI program. Once the child is linked to the EI provider there are also barriers to helping the family successfully reach the goals set for a child prior to completion of an EI program and the transition into a preschool or other education setting.

The IHP has been focused initially on ensuring hospitals provide hearing screenings for all infants using established protocols, providing appropriate explanations of failed screening results to families, referring or providing referral appointments, and reporting individual screening results to the IHP. Some of the concerns addressed have been ensuring the infant is screened at an appropriate time, that every infant, if at all possible, is screened prior to discharge, that multiple rescreening is not done in an attempt to obtain a “pass” result, and results are properly documented and reported to the IHP in a timely manner. Recently the IHP has been focused on reviewing hospital policies to ensure compliance with the revised Ohio Administrative Code that will be effective December 1, 2019.

Ensuring each infant that fails a hearing screening receives evaluation is a second challenge with many possible barriers. Assuming the hospital has helped set up an appointment, there are common family barriers that may prevent them from keeping the appointment and completing the evaluation. Among these are barriers to reaching the provider such as lack of reliable and affordable personal transportation, other family members’ schedules, parent work schedules that may not allow paid time off, as well as inconvenient location of provider office, poor preparation of infant for appointment, and inability of provider to complete evaluation at one time. In some instances, families have other priorities and do not perceive the need for follow-up hearing testing as a high priority.

Medicaid managed care programs will provide transportation to eligible families but there are challenges with the need for planning and advance notice to the transportation provider. In a research grant utilizing WIC offices, it was noted that clients were more likely to keep appointments when they could easily reach the provider offices by bus. In some instances, transportation vouchers have been provided to families to assist them with keeping scheduled appointments. In addition to educating providers, the IHP has utilized OCECD to also inform parents and guardians of this resource. The IHP program has encouraged and educated providers

to inform families the infant should be fed and ready for a nap immediately prior to beginning the evaluation.

Once an infant is diagnosed with a permanent hearing loss, there are barriers to ensuring the infant is enrolled in and provided with on-going EI services. The first challenge is helping the family to understand and accept the diagnosis, understand the need for and importance of EI, and to encourage follow through with recommended actions. The IHP has offered information to providers to ensure they understand where or how to make a referral for services to the family and has previously sponsored a seminar for audiologists in understanding and addressing family emotions.

Repeated attempts have been made to reach families who choose not to follow-up on EI. OCECD has noted in the past that some families may be in denial or need a period of time to grieve before they are ready to begin EI and they have periodically reached out to them over extended periods as well as ask if a better time in the future would be more appropriate to provide support to families.

Sometimes families do not trust or want to be participants in public programs. In other instances, there may be family issues, health and others, that prevent hearing loss from being a priority. In addition to these general concerns, there may be family concerns with other appointments for assessment for EI and setting goals, introducing EI providers, and developing the trust to allow them into their home.

The Ohio EI program within DODD is fully committed to serving families, but their protocols may be slightly different. DODD has expanded the use of tele-intervention technologies for hearing specific services in eight-five percent of Ohio's counties so many home visits will be done virtually. Although this may eliminate some family concern about letting another individual into the home, the challenges of reaching out in this manner will be ensuring secure connectivity for privacy reasons, re-designing family education material that be optimal for use via tele-intervention, and ensuring families have access to the appropriate technology at no additional cost. The IHP and DODD are committed to working collaboratively with one another and respect each agency's ability to evaluate the quality and acceptability of the services provided.

Stepping back from the individual family perspective, and looking at the broader picture, there are barriers related to collaboration with providers. Although Ohio hospitals and screeners primarily need ongoing monitoring, much more work needs to be done with the clinical community outside of the hospital setting.

The IHP continues to send letters to pediatricians identified as the primary care provider of infants with failed screenings to remind them of the need to schedule referrals. The IHP has previously collaborated with the AAP Chapter Champion to provide pediatricians with basic information on referral schedules but more outreach and education is needed to ensure these infants receive appropriate referrals to other specialists periodically.

Another challenge has been working with the audiological provider community to develop minimal standards statewide for diagnostic evaluation and periodic follow-up. Loss to documentation continues to be a challenge with diagnostic audiologists reporting evaluations in a timely manner.

A major challenge will be the development of linkages and collaborative efforts within the provider community for the development and dissemination of ongoing care coordination plans within the framework of a family centered team. This is a huge undertaking given that providers are being asked to take time, generally not billable, to build and participate in a broader

plan for each family when they are focused on providing their particular services under the most efficient possible timeline.

Another challenge for the IHP will be finding and funding a sustainable DHH adult-to-family support system. Infants diagnosed with hearing loss are located throughout Ohio's eighty-eight counties and providing consistent access to the various family support services is challenging. Although most of the families and infants with hearing loss are located in large urban areas, families living in remote, rural, and Appalachian communities need equal access to services and an opportunity for their voices to be heard.

### **Evaluation and Technical Support**

The IHP is committed to continuing its efforts to track all infants who fail a hearing screening, facilitate linkages for further evaluation, and to connect the families with EI services when infants are diagnosed with permanent hearing losses. As a part of that effort, the IHP will continue to utilize the IPHIS and Hi\*Track data bases and coordinate closely with a public health researcher to collect data, monitor and analyze quantitative data, and take corrective action as identified to improve outcomes. The IHP will utilize QI methods to implement small tests of change and collect data to assess the impact of these efforts to incrementally improve outcomes for families.

The IHP will also be collecting and reviewing process data for some initiatives and activities to better understand how successful outreach and training efforts are with selected cohorts, to learn what materials and information are most useful to the various audiences, and to determine what type of outreach is most likely to impel change in the targeted audience. The IHP will also be coordinating with a Family Group or groups to review and assess effectiveness of outreach to families of infants and toddlers with a hearing loss with a goal of improving their participation in planning and outreach beyond their individual communities.

Although EI service provision has been transferred to DODD, the IHP continues to have regular contact with them and will provide technical assistance and training as needs are identified. Our mutual goals are to ensure that the EI referrals, assessments, enrollments, and program services, from a family perspective, are seamless.

### **Organizational Information**

a. The Early Hearing Detection and Intervention program for the state of Ohio is housed within the Ohio Department of Health (ODH). The Department is a public, statewide agency, and the Director is appointed by the Ohio Governor to protect and improve the health of all Ohioans by preventing disease, promoting good health, and assuring access to quality care. The EHDI program, known as the Infant Hearing Program (IHP), is housed within the Bureau of Maternal, Child, and Family Health. Among the priorities of the Bureau are increasing comprehensive newborn screening and increasing the prevalence of children receiving integrated physical, mental and developmental services.

The Infant Hearing Program is part of a unit for Child and Specialty Health Services. The unit includes genetics, newborn heart disease screening, sickle cell, children's vision, and a state-funded hearing aid assistance program. The EHDI Coordinator manages the IHP staff including two Public Health Audiologists that are key to program implementation.

b. An administrative specialist provides in-kind office support, and other units within the Department provide fiscal services for grants management, payroll, accounting, and auditing.

The Department provides office space, telephone systems, computers and information technology support.

Internal partners such as Women, Infants, and Children (WIC) and the Children with Medical Handicaps (CMH) are supportive and assist with locating families. The IHP works closely with external partners, particularly the Ohio Department of Developmental Disabilities to ensure identified children receive linkages to early intervention. The program is also supported with data collection and management initiatives through Centers for Disease Control funding and by the expertise and support of the National Center for Hearing Assessment and Management as well as by the professional and family members of UNHS Advisory Subcommittee.

The Public Health Audiologists, as the key staff in the program, are focused on educating and supporting the hospital screeners and monitoring the hospitals, and then on educating, tracking and monitoring referred infants who may be deaf or hard of hearing as well as providing oversight for the family contracted services. Other key staff are the Data Entry Operator who assists with outreach and correspondence with providers and data input, and a Public Health Researcher, supported by a grant from the CDC, who is responsible for monitoring the electronic data system, tracking, analyzing and evaluating infant hearing screening, diagnosis, and early intervention enrollment data. Please see Attachment 5 for an organizational chart.

c. Program staff were invited to participate in determining the specific initiatives that were most important to strengthening the hospital screeners and the diagnostic audiology providers. Discussions were also held with the professionals and families of the UNHS Advisory Subcommittee regarding the priorities of the activities that were proposed. Senior management reviewed and signed off on the plans for the coming year. The program supervisor believes the chosen initiatives are reasonable and the program staff have the skills to implement them. The Bureau Fiscal Liaison and the ODH Office of Fiscal Affairs, will be monitoring expenditures, tracking personnel costs and coordinating periodic federal fiscal reports and fund drawdowns. The Office of Fiscal Affairs also tracks periodic Time and Activity reports to ensure staff are working on allocated projects within allocated time frames. Their activities will ensure program expenditures are handled within appropriate federal guidelines and restrictions to prevent audit findings.

d. All demographic data for mother and baby's screenings are reported to the State's electronic birth records. The IHP uploads this data into the Hi\*Track database where pediatric audiologists can enter data on diagnostic evaluations and status into Hi\*Track. This data is then used by internal staff and trained contractors, to reach out to families of infants and toddler with a confirmed permanent hearing loss. The IHP goal is to reach every family and link them to appropriate early intervention service for their child or to document their participation in private early intervention service.

Data in both the electronic birth record and in Hi\*Track are regularly monitored to ensure appropriate contact is made with physicians and families and that infants and toddlers receive the screening, diagnosis, and early intervention referrals they need. The Public Health Researcher coordinates with Information Technology staff to resolve problems and regularly update records. The Public Health Researcher has expertise in data analysis and runs periodic reports to review trends, identify family or child characteristics that need further attention or exploration, and creates regular reports for newsletters and for the UNHS Advisory Subcommittee.

e. As mentioned previously, the IHP has developed collaborative partnerships with other units within ODH, often serving the same families, to assist in outreach and provision of services. The UNHS Advisory Subcommittee mentioned above includes professionals who

serve families with deaf or hard of hearing infants and toddlers and these nurses, physicians, audiologists, speech pathologists, and families of children who are deaf or hard of hearing generously share their knowledge and skills with the IHP as we all strive to reach our common goals of providing for the needs of deaf and hard of hearing infants and toddlers.

The IHP has access to experts from Medicaid and links to the Ohio Speech and Hearing Professionals Board. The IHP does outreach to physicians and families identified in-house but the IPH also contracts with the Ohio Coalition for Education of Children with Disabilities. Their trained, passionate, and compassionate staff provide additional outreach to families to assist with linkages to early intervention services. The IHP is committed to reaching out to other professionals, service providers, and families as the program attempts to ensure the needs of all children are met.