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Project Title: Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening
Organization Name: Washington State Dept. of Health Early Hearing-loss Detection, Diagnosis, and Intervention (EHDDI) Program
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Accomplishments and Barriers

This progress report describes our work to date, as well as information on what we plan to accomplish by March 31, 2015, regarding the aims and strategies outlined in our proposal. Highlights of our accomplishments include:

- Developed and implemented targeted strategies at hospital based screening programs to decrease loss to follow-up
- Conducted multiple site visits and trainings for hospital based screening staff
- Enhanced the EHDDI tracking and surveillance system to allow audiologists access to all infants born in Washington rather than just infants who we show as having been referred to them. We received approval for this from our Enterprise Records Management Office and our Information Security Officer to make this change.
- Organized four online pediatric audiology learning sessions to be held in early 2015. Each session will have a 30 minute presentation on a topic relevant to pediatric audiology, followed by 30 minutes to share and discuss de-identified case studies.
- Surveyed 690 primary care providers who we show as having received a follow-up fax from the EHDDI program in 2013.
- Continued our work to integrate Early Support for Infant and Toddlers (ESIT, Washington's Part C) data into the EHDDI tracking and surveillance system

The EHDDI program has not experienced any major barriers in achieving the aims outlined in this grant. However, an upcoming obstacle we will be facing in the next legislative session is a proposed cut of all of our state funding. If this funding is cut, our contracts with Hands and Voices and Seattle Children's Hospital will be terminated.

Goals and Objectives

As guided by HRSA, the EHDDI program outlined Aims and Strategies rather than Goals and Objectives in our original application. In this report we describe our progress on selected strategies. If we have not begun work on a strategy, we have excluded it from this report.

Aim 1
By August 31, 2017, increase the percent of infants born out-of-hospital who receive a newborn hearing screen by 25%.
Strategy 1.1: Have newborn hearing screening and follow-up included in the curriculum at the Master of Science in Midwifery program at Bastyr University.
Status: Completed. The topic of newborn hearing screening has been included in the curriculum of the Genetics and Embryology class at Bastyr University's Midwifery Degree Program. As part of this instruction, a Guide By Your Side™ (GBYS) parent guide will share with the class his/her story as a parent of a child with hearing loss. In 2015, this material is scheduled to be covered by the class in March.

Strategy 1.2: Work with Guide By Your Side™ (GBYS) to submit an article that includes a story from a parent of a child with hearing loss in the Midwives' Association of Washington State's (MAWS) Newsletter.
Status: In Progress. We have discussed this idea with Kristina Wendorf, a GBYS parent guide. She is interested in collaborating with us to write this article and we will begin writing an article in January 2015.

Strategy 1.5: Work with hospitals and communities to ensure information about newborn hearing screening is included in child birth preparation classes.
Status: In Progress. To pilot this project, we have chosen three hospitals that do not perform outpatient rescreening in rural southwestern Washington. We will work with the childbirth educators at these three locations to determine what, if any, hearing screening information is already provided and how best to improve this for future classes. We plan to encourage use of the Genetic Alliance's Baby's First Test video and handouts, as well as our own brochures. We have also contacted two popular organizations that provide education and certification for childbirth educators so we can incorporate hearing screening education into these educator trainings as well. Finally, we learned of the Regional Association of Childbirth Educators of Puget Sound (REACHE) conference and are planning a booth at the next meeting in March 2015.

Aim 2
By August 31, 2017, decrease the number of infants who fail to receive a second hearing screen after not passing their initial newborn hearing screen by 200 infants.

Strategy 2.1: Conduct site visits to hospitals that have refer rates of greater than 10% or percent infants lost after not passing the initial screen of greater than 10%. During the site visits, we will recommend small tests of change like using scripts, implementing annual competencies, and using the National Center for Hearing Assessment and Management (NCHAM) training curriculum.
Status: In Progress. Since September 1, 2014, EHDDI staff have visited four hospitals that have refer rates of greater than 10%: Toppenish Community Hospital (rural/South Washington), Providence St. Mary Medical Center (rural/South Washington), Othello Community Hospital (rural/Central Washington), and St. Elizabeth Hospital (rural/West Washington). At Toppenish we stressed that they needed to decrease the number of hearing screeners and have a lead screener responsible for coordination and care of equipment. We also encouraged them to

provide hearing screening observation for staff as part of their annual competencies. At Providence St. Mary Medical Center, EHDDI staff encouraged screeners to perform a second screen just before discharge since they were losing so many infants after an initial not passing screen. We also reviewed proper probe insertion. At Othello Community Hospital, we focused on retraining staff on how to use their ABR equipment, which they recently purchased and have had trouble using. At St. Elizabeth Hospital, EHDDI staff encouraged them to have a core group of screeners to mentor others since they have many screeners. We also covered proper OAE probe insertion, how to report refusals to the EHDDI program, and encouraged them to provide observation as part of annual competencies.

Strategy 2.2: Conduct small tests of change for the follow-up protocol that is initiated after the provider informs the EHDDI program that he/she has referred an infant or shared the recommendation to get a second hearing screen with the family. For example, when providers respond as shared, attempt to determine where baby referred rather than closing case.
Status: In Progress. Historically, when a primary care provider (PCP) tells EHDDI program staff that an infant has been referred to a certain clinic or hospital for a follow-up hearing screen, we generated an action to contact that hospital or clinic in 3 weeks to obtain the hearing screening results if they have not already been sent to the EHDDI program. In looking at data from the first six months of 2014, we recently determined that we were contacting hospitals and clinics too early to get hearing screening results. On average, hearing screens were completed just three days before we contacted the hospital or clinic to obtain the hearing screening results. This does not allow enough time for the facility to send us results on hearing screening cards, which would eliminate the need for the EHDDI program to contact the hospital or clinic for results. We also found that, on average, we were receiving the hearing screening results 20 days after we contacted the hospital or clinic. Due to these findings, we believe EHDDI staff are contacting facilities too early and are sometimes missing hearing screening results because they have not yet been done or recorded. We are testing the strategy of generating an action to contact that hospital or clinic in 70 days, rather than 3 weeks. In six months, we will look at tracking and surveillance data to determine if this change has increased efficiency within the EHDDI program and increased the number of cases where we obtain accurate hearing screening information.

Strategy 2.3: Conduct small tests of change on how the EHDDI program tracks responses from hospitals who receive the Did Not Pass – No Record of Rescreen (DNP) Report. For example, keep log of which hospitals do not respond and contact those hospitals to encourage responses.
Status: In Progress. EHDDI program staff generally send the DNP Report at the end of each month. This report lists infants born two months prior who did not pass their initial screen and for whom we still do not have a follow-up screen. On November 25, we sent the DNP report to 29 hospital coordinators and tracked responses. Without further follow-up, we only received 12 (41%) reports back from hospitals. Next month we will test the strategy of faxing the report again and sending a reminder email if the coordinator has not faxed the report back in one week.

Strategy 2.4: Include the specific topic of second hearing screens at the annual Newborn Hearing Screening Meeting, highlighting the importance of a child getting a rescreen by one month of age and the nuances of reporting the results to the EHDDI program.
Status: In Progress. We are currently working with Seattle Children's Hospital, who we contract with to host the Newborn Hearing Screening Meeting, to set the dates and draft the

agenda for the meetings in Spokane and Seattle in 2015. The first item on the agenda will likely be an update from the Washington State EHDDI program. We plan to use some of this time to discuss best practices for second hearing screens and reporting results to the EHDDI program.

Strategy 2.5: Work with hospitals to test the strategy of having the hearing screener get an email or cell phone number from the family when an infant does not pass his/her hearing screen. The screener will then send an email or text that includes a link to a video using parent stories to highlight the importance of newborn hearing screening and follow-up. The email or text will also include a reminder of the date, time, and location of the infant's scheduled rescreen.
Status: In Progress. We are currently testing this strategy through Plan-Do-Study-Act (PDSA) cycles with Overlake Medical Center. Since Overlake Medical Center does not do in-patient initial hearing screens, the hospital has a high percentage of infants who do not receive a hearing screen. In the first quarter of 2014, 4% of infants born at Overlake missed their newborn hearing screen. Overlake agreed to work with us on a strategy to send an email to the family that is not bringing their child in for a hearing screen. The email contains a reminder message, a link to an informational newborn hearing screening video (a CNN news story - https://www.youtube.com/watch?v=IVdrAQfuSB4), and is signed as being from the chief of pediatrics at Overlake Hospital. The first cycle of this PDSA began November 1, 2014.
The results of the first cycle, which ended December 4, were disappointing. Of the eight families who refused to come back to Overlake for a hearing screen, none were willing to give their email to receive the information and video. We have yet to discuss these results in detail with Overlake's newborn hearing screening coordinator, Sandy Salmon, but we believe that families who are refusing their hearing screen will be more resistant to give their email address for a follow-up communication. In the coming week, we will talk with Sandy about this first PDSA cycle and her ideas for improvement. We would like to revise the strategy for the next PDSA cycle to include Overlake's UNHS program arrange for an inpatient hearing screen if the family indicates at the hospital that they will be going to their pediatrician or another clinic for their post-partum care rather than returning to Overlake.

This PDSA focuses on missed hearing screens and we are also attempting to locate other hospitals willing to work with us that have difficulties in getting infants in for rescreens after not passing their newborn hearing screen. We have reached out to Forks Community Hospital, since 24% of the infants born in 2013 did not return for follow-up screening after not passing their initial hearing screen. We have not yet heard from Forks that they will work with us to try this strategy and we are looking at other possible hospitals with which to partner.

Strategy 2.7: Modify the action EHDDI staff take after we find out that an infant has moved out of state, such as developing a letter to send to other state EHDI programs to inform the new state of residence and attempt to get follow-up data as well as working more closely with Oregon regarding border babies.
Status: In Progress. We have been working more closely the Oregon EHDI program regarding follow-up of border babies. One EHDDI staff member recently joined the OR EHDI Advisory Committee to help promote interstate communication efforts. The two state programs have begun discussing more efficient and secure ways to email/send data regarding the other state's residents. We also created a new code in our EHDDI-Information System (IS) to help identify

babies born in other states but that currently live in or receive EHDDI related services in Washington.

Aim 3
By August 31, 2017, decrease by 15% the percent of infants who fail to receive a conclusive diagnostic evaluation after being referred to audiology due to not passing their hearing screening.

Strategy 3.1: Design and conduct small tests of change on the protocol we use to contact parents after they do not bring their infant in for a needed diagnostic evaluation.
Status: In Progress. Last year we began sending letters to families who we found were not bringing their child in for a needed diagnostic evaluation. We asked families to complete a form with information about where they will or have taken their child to an audiologist, and mail it back to us in a self-addressed, postage paid envelopes we enclosed with our letter. After several months of testing, we received no forms back from families and we did not see an increase in follow-up due to our letters. Since this follow-up letter was unsuccessful, we have decided to try calling families. We have contacted GBYS to request that a GBYS representative train EHDDI staff on contacting parents with appropriate sensitivity and guidance. We also contacted Oregon's EHDI program to get their scripts for contacting parents and receiving calls from families. We are collecting this information to incorporate it into the new follow-up protocol. We plan to begin implementing the new protocol by April 1, 2015.

Strategy 3.2: Enhance the EHDDI web application to allow audiologists to search for all infants born in the state, rather than just the infants referred to their clinic (the EHDDI program has already received approval for this from our Enterprise Records Management Office and our Information Security Officer).
Status: Completed. Since September 2014, audiologists have been able to use our secure EHDDI web application to search for all infants born in the state. This was accomplished by working with our vendor, Neometrics, for several months to test and then implement the change. We have received positive feedback regarding the change from several audiologists who use our online system. Along with this enhancement, we also requested that Neometrics have the system notify us when an audiologist has entered a diagnostic result for an infant. This allows us to go to that case and review the information shortly after a result is reported by an audiologist. This helps us ensure quality reporting and alerts EHDDI staff to potential follow-up concerns.

Aim 4
By August 31, 2017, increase the percent of infants who receive a conclusive diagnostic evaluation by 3 months of age by 25%.

Strategy 4.1: Create a checklist of items we want to cover with audiology clinics during our site visits.
Status: Completed. EHDDI staff drafted an Audiology Training Checklist, which outlines the topics we will review with audiologists during our trainings. The main areas noted in the checklist are: audiology clinic statistics, reporting, EHDDI-IS web application, referring to a Family Resources Coordinator (FRC), best practice protocols, resources, EHDI-PALS, the Seattle Children's audiology toolkit, and self-assessment for audiology clinics. We included time

for audiologists to tell us how EHDDI can better support audiologists and an opportunity to provide us with general feedback, questions, or concerns.

Strategy 4.2: Host quarterly grand rounds/case studies for audiologists to reinforce best practices.
Status: In Progress. In collaboration with Seattle Children's Hospital, we organized four online pediatric audiology learning sessions to be held in 2015. Each session will have a 30 minute presentation on a topic relevant to pediatric audiology, followed by 30 minutes to share and discuss de-identified cases. There is no cost to audiologists and American Speech-Language-Hearing Association (ASHA) Continuing Education Units (CEU) will be offered. The series schedule is as follows:

- January 8, 2015 - Audiological Management of Children with Cytomegalovirus (CMV) presented by Dr. Henry Ou
- February 5, 2015 - Genetics and Hearing Loss presented by Linda Ramsdell, MS, LCGC
- March 5, 2015 - Audiological Monitoring of Children with Middle Ear Involvement presented by David Horn, MD
- April 2, 2015 - Best Practices for Brainstem Auditory Evoked Response presented by Anupa Gaddam, AuD

Strategy 4.3: Work with Seattle Children's Hospital to explore possibility of a pilot tele-audiology site in a region with high loss to follow-up.
Status: In Progress. Laura Steinmetz, the audiologist we work with through our Seattle Children's contract, submitted a tele-audiology proposal and needs assessment to the Director of Audiology at Seattle Children's Hospital, Dr. Susan Norton. We identified two communities that have high loss to follow-up and no local pediatric audiology clinics. In one of these communities, Longview, Washington, there is already a satellite Seattle Children's clinic with video conferencing equipment. Since Longview has a significant need for local pediatric audiology services and there is already infrastructure in the community, Dr. Norton is interested in pursuing a tele-audiology site in Longview and is investigating possible funding sources to purchase the audiology equipment necessary for a tele-audiology project. If funding is found, the proposal would be then need to be reviewed and approved by the Seattle Children's tele-medicine program.

Strategy 4.4: Survey providers about their knowledge of newborn hearing screening and follow-up, specifically asking them about the need for infants with atresia to return to audiology after having a medical evaluation/treatment with an Ear, Nose and Throat (ENT) doctor.
Status: In Progress. In November 2014, EHDDI staff sent out surveys to 690 providers who we show as having received a follow-up fax from the EHDDI program in 2013. In the survey, we asked providers their level of agreement (strongly agree, agree, disagree, strongly disagree, or unsure) to the following statement: "It is very important for an infant with unilateral atresia to have his/her hearing evaluated by an audiologist after an ENT medical evaluation/treatment."

Surveys are still being returned to us, but of the 227 providers who have so far responded to this question, 155 (68%) strongly agreed with the statement, 43 (19%) agreed, 1 disagreed (0.4%), and 17 providers (7%) strongly disagreed with the statement. Eleven providers (5%) were

unsure. These responses indicate that the majority of providers understand the need for a hearing evaluation after an ENT medical evaluation/treatment. However, often during our follow-up of infants with atresia we do not see this occurring. If providers understand the need for a hearing evaluation, there must be other barriers that prevent audiologic follow-up after a child is seen by an ENT specialist. The EHDDI program will be discussing this with our stakeholders to identify what those barriers may be and how to remove them.

Strategy 4.5: Work with Washington's American Academy of Pediatrics (AAP) Chapter Champion to offer educational opportunities or information for providers that explain and clarify the importance of an infant receiving a diagnostic evaluation before three months of age. See S3.3 for associated educational strategy.
Status: In Progress. As noted in Strategy 4.4, the EHDDI program sent out a provider survey in November. In the survey we asked providers about their knowledge of newborn hearing screening and follow-up and their preferences for resources and education. Of the 690 surveys we sent out, we have so far received responses from 238 (34%). Surveys are still coming in and we expect that our provider response to the survey will be 45-50%. We plan to use the results from this survey to work with our AAP Chapter Champion to design educational opportunities or resources for our providers.

Strategy 4.6: Conduct site visits with audiology clinics to review reporting, diagnostic practices, scheduling, and follow-up.
Status: In Progress. We have not conducted any audiology trainings since September 1, 2014, but we have four scheduled in December:

- Dec. 10, 2014 - Chasity McCrum and Jessica Smith who split time between Confluence Health Omak Clinic Audiology, Confluence Health Wenatchee Valley Medical Center Audiology and Confluence Health Moses Lake Clinic Audiology
- Dec. 10, 2014 - Megan Carter at the Eye and Ear Clinic of Wenatchee
- Dec. 10, 2014 – Walter Horan, Justin Fevold, and Bridget Arseneault at Horan and Fevold Hearing Clinic
- Dec. 11, 2014 - Sally Rogers at Yakima Valley Hearing and Speech Center

Aim 5
By August 31, 2017, increase the percent of infants who have hearing loss who are referred to the Early Support for Infant and Toddlers (ESIT) program through the EHDDI-IS by 30%.

Strategy 5.1: Conduct trainings for audiologists in how to use the EHDDI web application and document referrals.
Status: In Progress. As noted in Strategy 4.6, we have not conducted any audiology trainings since September 1, 2014, but we have four scheduled in December 2014. In three of these trainings, we will be teaching audiologists how to document referrals using the EHDDI web application. One of the clinics, Eye and Ear Clinic of Wenatchee, will not be using the web application and will not be getting the web application training during our site visit.

Strategy 5.2: Work audiologists and ESIT to improve the EHDDI web application (e.g. have EHDDI-IS send diagnostic results to ESIT when an infant is referred to ESIT through EHDDI-IS).
Status: In Progress. We have talked with our contacts at ESIT about our desire to send an infant's diagnostic results that the audiologist has entered along with the referral to ESIT. We have also told our vendor, Neometrics, that this system enhancement is a priority. However, we have not yet received information from ESIT on how they would be able to accept diagnostic information from the EHDDI system. We imagine that it could be sent to them as added data fields or potentially in an attached document/report. We hope to get clarification about how these data could be transferred by February 2015.

Aim 6
By August 31, 2017, improve access to family support services in Washington for families with children who have hearing loss.

Strategy 6.2: Contract with Hands and Voices to continue building the GBYS program to support families of children at risk for or diagnosed with hearing loss, such as through increasing outreach/education to community organizations and initiating referrals to families before final hearing loss diagnosis (see S1.2, S1.7, S3.5, S3.7, and S6.5).
Status: Completed. We have established a contract with Hands and Voices from this HRSA grant and more from state funds) to support the GBYS program. We are also working with Washington State's Department of Social and Health Services Office of Deaf and Hard of Hearing (ODHH) to help further support GBYS. We are hoping to amend our current contract with GBYS to include additional funding from ODHH.

Strategy 6.3: Continue to participate in the multi-agency team that has designed and is now working on implementing the State Plan to ensure families with children who have hearing loss receive timely and appropriate early intervention (EI) services.
Status: In Progress. Our Deaf/Hard of Hearing (/D/HH) Agency Task Force has a meeting scheduled for January 22, 2015. We will discuss progress that has been made in implementing our State Plan, next steps in accomplishing our goals, and possible adjustments we feel need to be made to the State Plan. We have identified that funding is a major barrier in achieving our goal of ensuring families with children who have hearing loss receive timely and appropriate services. To help overcome this obstacle, we have begun to discuss entering into a private-public partnership with hospitals, audiologists, and/or EI programs to collaboratively apply for grant funding to support our efforts and explore using tele-intervention more extensively in Washington State.

Significant Changes

There have been no significant changes in our project plan or personnel since our original HRSA grant application.

Plans for Upcoming Budget Year

There are no major changes to the Work Plan that was submitted with our original 2014 HRSA grant application. We plan to address the aims and strategies that were noted as being achieved in the coming budget year. In summary, the activities that will be performed include:

- Continue developing and implementing targeted strategies at hospitals to decrease loss to follow-up in three key areas: after a missed initial screen, not passing the initial screen, and after being referred to audiology.
- Collaborate with GBYS to develop our protocol and scripts for calling parents after they do not bring their infant in for a needed diagnostic evaluation.
- Use the results from our survey of primary care providers to work with our AAP Chapter Champion to design educational opportunities or resources for our providers.
- Host online pediatric audiology learning sessions where topics relevant to pediatric audiology are presented and anonymous case studies are reviewed.
- Work with the ESIT program to improve the data exchange module and train audiologists and FRCs on how to use the exchange.
- Conduct site visits with audiology clinics to review reporting, diagnostic practices, scheduling, and follow-up.
- Continue to support Early Head Start programs in Washington in their efforts to screen infants for hearing loss and ensure appropriate follow-up for infants diagnosed with hearing loss.
- Work with our partners to implement and further develop the State Plan to ensure families with children who have hearing loss receive quality early intervention (EI) services.